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**Families of People with Experience of Psychosis:
Exploring the Impact of Family Interventions and Understanding the Role of
Young People in Their Parent's Care**

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Doctorate in Clinical Psychology
The University of Edinburgh
May 2017

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Acknowledgements

First and foremost, I would like to thank the young people who took part in the research. Without their time, willingness and openness in sharing their experiences, this piece of work would not have been possible. Thank you to their families, young carer workers and NHS staff who provided support for young people to take part. A huge thanks also to the parents, young people and members of the Scottish Children's Research Network Young Person's Group who provided feedback and advice in the early stages and planning of the research. Their advice and recommendations were invaluable in helping me to think about how the research could be conducted in a way that remained sensitive to and acceptable to young people and their families.

A special thanks to my academic supervisor, Dr Emily Taylor. Thank you for your support and guidance, for sharing your wealth of experience and expertise and for your encouragement and containment during times of stress! Thanks also to my clinical supervisor, Dr Amy McArthur for your time and for always stopping to offer a few kind words in the corridor! I would also like to acknowledge Tara Graham, Patrick Doyle, Dr Fay Crawford, Dr Laura Walton, and Dr Kirsty Gillings for your support and input.

The supportive role of family is a theme that runs throughout this thesis and having the support of my family and loved ones is certainly something that has helped me along this road. I would like to say a huge thank you to my fiancé, Alex. Thank you for always believing in me, for making me laugh and for your endless support and patience. A special thank you to my Mum for always being there, for listening and for the parcels, notes and flowers to keep me going! Thanks also to my Dad for checking in with the workload but keeping me grounded, and to Simon, Lucy and Jack for your ongoing support. A huge thank you to all my family and friends for being there for me, for providing me with perspective, hope and encouragement when things were tough and for gently reminding me why I set out on this journey.

Terminology and Conceptualisation of Psychosis

The focus of this thesis is on families of people with experience of psychosis. This includes families of those with experience of schizophrenia-type disorders and bipolar disorder. According to the American Psychiatric Association (2013)¹, hallucinations, delusional beliefs, disorganised speech and/or motor behaviour and negative symptoms are common features of psychosis. It is acknowledged that for some people, it is useful to conceptualise these experiences in the context of mental illness and diagnoses but for others, it can be helpful to consider psychosis as part of a continuum of human experience. It is therefore difficult to establish a common language that is accepted universally.

Generally, diagnostic terms are used within existing literature and for ease of communication, will be adopted here where relevant. The term *psychosis* is often used to describe a range of mental illnesses in which *psychotic symptoms* may occur and this term will therefore be adopted to encompass schizophrenia-type disorders and bipolar disorder. For clarity and ease of communication, *psychotic symptoms* will be used to differentiate discrete experiences such as hearing voices (*hallucinations*) or having extremely suspicious thoughts (*delusional beliefs*). Despite making a decision with regard to the use of language within the write-up of this thesis, the subjectivity of experience is acknowledged and on speaking with those who took part in the research (and their families), language was guided by how experiences of psychosis were discussed and conceptualised by individuals and their families.

¹ Full reference listed within *Thesis References* (page 125)

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Chapters within this thesis are formatted in line with author guidelines pertaining to journals specified at the beginning of each chapter. In accordance with thesis requirements outlined by the Doctorate in Clinical Psychology (University of Edinburgh/NHS Scotland Clinical Psychology Training Programme) Research Handbook and associated guidelines (2016/2017), margins have been adapted to meet requirements outlined and tables and figures have been inserted within text. Author information and contact details have also been omitted and appendices are more extensive for the purpose of thesis submission. As separate articles are presented within the thesis, running heads are presented on the first page of each chapter only.

Total word count: 23, 771

(including figures & tables; excluding references & appendices)

Thesis Abstract

Background: While literature indicates a positive impact of family interventions (FIs) on people with experience of psychosis, less is known about outcomes for other family members involved with these interventions. Furthermore, there is a paucity of literature offering an understanding of how young people with a parent with experience of psychosis view themselves in relation to their parent's care. In the context of community care for psychosis, consideration of family views and outcomes is important in establishing how their needs may best be met.

Aim: The thesis aims were twofold: (a) to systematically review the literature to explore the impact of single FIs for psychosis on family members, establish whom outcomes are being gathered for, and to what extent children and young people are involved; and (b) to develop an understanding of how young people with a parent with experience of psychosis conceptualise themselves in the context of their parent's care.

Method: A systematic search of the literature was conducted in October, 2016. Additionally, 12 interviews were carried out with 11 young people (aged 14-18 years) with a parent with experience of psychosis. A grounded theory approach was employed.

Results: 21 studies were included in the systematic review. 86% revealed at least one positive outcome for family members engaging with FIs. None of the studies included children or young people. In the empirical study, a provisional theory was generated and at the core of this is how young people establish and negotiate their role in relation to their parent's care in the context of adolescence; balancing caring for and/or living with a parent with experience of psychosis with "being a teenager". This process appears dependent on young people's perception of parental needs and supports and among other factors, seems to be facilitated by having appropriate information (that is specific and formulation based). Young people perceiving adults to view them as "too young" appears to be a significant barrier to this.

Conclusion: The systematic review points towards a generally positive impact of FIs on family members but involvement of children and young people is lacking. The empirical study highlights that parental psychosis appears to pose additional and unique challenges to young people, particularly in the context of adolescent development; emphasising the need for better support, appropriate information sharing and adults recognising and validating young people's experiences. Future research would benefit from the exploration of inclusion of children and young people in FIs.

Running head:

FAMILY INTERVENTIONS FOR PSYCHOSIS_FAMILY OUTCOMES

Chapter One

Outcomes for Family Members Engaging in Single Family Interventions for Psychosis: A Systematic Review

The review is written in accordance with author guidelines for Clinical Psychology
Review (Appendix A).

Abstract

While literature indicates a positive impact of family interventions on those with experience of psychosis, less is known about the effect of these interventions on other family members engaging with them. The review aimed to explore the impact of single family interventions for psychosis on family members, establish whom outcomes are being gathered for and to what extent children and young people are involved. A database search of Embase, Medline and PsycINFO was conducted in October, 2016. Grey literature was also searched and included studies were assessed for quality using a tool developed for this review. 21 studies met criteria for inclusion. Findings indicated outcomes exploring wellbeing and family interactions to be most prevalent. 86% of studies revealed at least one positive outcome. None of the studies included children. Small sample sizes, high attrition rates and lack of fidelity measures were among factors indicating poor methodological quality of studies. Findings point towards a generally positive impact of family interventions for family members of those with psychosis. Future research would benefit from the exploration of inclusion of children and young people in family interventions and increased methodological rigour, particularly in relation to comparison groups, sample size and treatment fidelity.

Keywords: family intervention, psychosis, relatives, outcomes, review

Highlights

- Family interventions for psychosis can have a positive impact on family members.
- Outcomes exploring wellbeing and family interactions are most prevalent.
- There is a lack of inclusion of children and young people in family interventions.
- Research exploring involvement of children and young people is required.

Introduction

Background

It is thought that 1-2% of the European population have a diagnosis of a psychotic disorder (McCrone, Dhanasiri, Patel, Knapp, & Lawton-Smith, 2008). Psychosis is characterised by experiences such as hallucinations, paranoia and delusional beliefs (which often cause distress) and is associated with high levels of anxiety and difficulties with social and occupational functioning (Gelder, 2005). This can have a significant impact on the individual and those around them (National Institute for Health and Care Excellence [NICE], 2014a). Family members often report positive experiences of living with and/or caring for someone with experience of psychosis, including strengthened family relationships and valuing a caring role (Gladstone, Boydell, Seeman, & McKeever, 2011; Kuipers, Onwumere, & Bennington, 2010; McCann, Lunman, & Clark, 2011). Despite this, the social, emotional and psychological impact of caring for those with psychosis is also acknowledged (Addington, Coldham, Jones, Ko, & Addington, 2003; Teschinsky, 2000). Research indicates that having a family member with schizophrenia remains a stressor for families (Friedmann et al., 1997) and is associated with high levels of *expressed emotion* (Hooley, 1985; Vaughn & Leff, 1976). Hooley and Parker (2006) defined expressed emotion as “the extent to which the close family members of an identified patient express critical, hostile, or emotionally overinvolved attitudes toward the patient” (p. 386). The recognition of expressed emotion within families prompted the development of family interventions (FIs) for psychosis with the initial aim of reducing stress in the family to promote positive outcomes for the affected individual. More recently, there has been a shift from reducing expressed emotion to

promoting information sharing and communication with the aim of increasing family wellbeing (McFarlane, Dixon, Lukens, & Lucksted, 2003). FIs are recommended for those with psychosis, schizophrenia and bipolar disorder (NICE, 2014a, 2014b; Scottish Intercollegiate Guidelines Network [SIGN], 2013) and through recognising the potential impact of schizophrenia on family and carers, carer assessments, psychoeducation and appropriate support to family members is advised (NICE, 2014a, 2014b; SIGN, 2013).

A wide range of FIs exist. These include psychoeducational packages and support groups that are often designed specifically to take in to account carer needs. Multi-family and single FIs typically include the family member with psychosis and are delivered to a group of families or on an individual family basis, respectively. A number of these interventions have been manualised (Falloon, 1985; Kuipers, Leff, & Lam, 1992, 2002; McFarlane, 1983). Although there is a degree of variation in the specific content of FIs, they may include elements such as psychoeducation and skill-based training (for example, communication and problem-solving skills).

Adaptations have also been made to take in to account factors such as cultural and diagnostic differences (Edge et al., 2016; Fiorillo et al., 2015; Razali, Hasanah, Khan, & Subramaniam, 2000). Despite the wealth of evidence highlighting the effect of FIs on relapse rates and hospital admissions in those with psychosis (Pharoah, Mari, Rathbone, & Wong, 2010), outcomes for family members have been less frequently explored (Lobban et al., 2013). As outlined by Lobban et al. (2013), this is problematic due to the possibility that reduced hospitalisation and relapse for those with psychosis may well be at a cost to the wellbeing of family members.

Furthermore, a review by Sin and Norman (2013) highlighted that when outcomes

for relatives of those with psychosis are reported, these tend to focus on knowledge, coping and perceived support as opposed to wellbeing or quality of life.

Reviews suggest that outcomes for FIs are seldom reported for (child) siblings or offspring of those with psychosis, with research having a greater focus on adult carers such as parents and spouses (Lobban et al., 2013; Sin & Norman, 2013). This makes it difficult to establish how young people may best be supported within the context of living with a parent with psychosis. Literature investigating the impact of living with parental mental illness (PMI) in general (which may include psychotic illnesses but is not specific to psychosis) highlights both positive and difficult aspects of this. A review of qualitative studies (Gladstone et al., 2011) indicates that in some cases, family relationships are perceived to be strengthened. However, there is a greater incidence of mental illness among young people living with PMI (Beardslee et al., 1996; Handley, Farrell, Josephs, Hanke, & Hazelton, 2001) and children often report having caring responsibilities for their parent (Caton, Cournos, Felix, & Wyatt, 1998). Gladstone et al. (2011) also reported that children frequently describe confusion and a lack of understanding regarding their parent's presentation and concluded that those who have knowledge about their parent's illness are better able to cope. With regard to parental psychosis, research indicates that children may struggle to make sense of psychotic symptoms and can feel disconnected from their parents and isolated from peers (Somers, 2007; Valiakalayil, Paulson, & Tibbo, 2004). This demonstrates the potential benefits of family work for these young people and has led to the acknowledgement of the need to include offspring in FIs and provide support to young carers (SIGN, 2013). Despite this, to the author's

knowledge, outcomes for young people engaging with FIs have not been systematically reviewed or synthesised.

A systematic review of interventions to support relatives of people with psychosis was published by Lobban et al. in 2013. The review identified 50 studies reporting outcomes for family members participating in a wide range of interventions including single and multi-FIs, support groups and psychoeducation only. Results indicated that 60% of studies reported positive outcomes for family members but that methodological quality was generally poor. While this review added to the knowledge base by exploring the impact of FIs on relatives of people with psychosis as opposed to patient outcomes, there was a great deal of heterogeneity in interventions included. This aimed to identify the key components of effective interventions but makes it difficult to establish the unique impact of specific interventions. The authors also acknowledge the limitation of only including randomised controlled trials (RCTs) in their review; perhaps risking the exclusion of more innovative interventions embedded within a family focused context. While Lobban et al. (2013) emphasised a focus on adult relatives and lack of adaptation of interventions for young people, the designation of family members included in studies was not reported.

Current Review

In light of recommendations for the delivery of FIs for people with psychosis, schizophrenia and bipolar disorder alongside the importance of ensuring that relative's needs are taken into account (NICE, 2014a, 2014b; SIGN, 2013), the current review will focus on single FIs designed for the inclusion of both the individual with psychosis and their family. As there is already a degree of difference

with regard to how single FIs are delivered and the theoretical model on which they are based, this focus aims to eliminate further heterogeneity by excluding multi-FIs, thus enabling more specific conclusions relating to a specific intervention type to be drawn. The aims of the review were threefold: (a) to establish whether single FIs for psychosis are effective in improving outcomes for family members (of those with psychosis) engaging with them, (b) to explore which outcomes are being measured and from whom these are being gathered, and (c) to establish the extent to which children and young people are included in single FIs and whether interventions and outcome measures used are developmentally appropriate for their involvement.

Method

Selection Criteria

Papers were included in the review if outcomes for family members (of all ages) engaging in single FIs for schizophrenia-type disorders, psychosis or bipolar disorder were systematically gathered and reported. Single FIs must have included ten or more family sessions involving the individual with experience of psychosis and at least one other family member. The number of sessions was informed by SIGN (2013) and NICE (2014a) guidelines. This criterion aimed to ensure that outcomes for FIs were captured as opposed to routine family involvement, psycho-education or support groups for family members only. Papers were only included if they reported primary data and were published in the English language. Given the exploratory nature of the aims of the review, both randomised and non-randomised studies were included. Furthermore, although RCTs are generally considered to be the highest level of evidence to determine intervention effects (The Cochrane Collaboration, 2011), their limitations in evaluating FIs are acknowledged. As

highlighted by Lobban et al. (2013), given the growing emphasis on integrating and embedding support for families within services, RCTs evaluating FIs are susceptible to confounding factors brought about by family involvement in comparison conditions. The inclusion of both randomised and non-randomised studies was therefore considered important.

Papers were excluded if: a qualitative methodology was adopted to gather information regarding family outcomes, the intervention was designed for dual diagnoses, the FI incorporated a multi-family therapy (MFT) component (and the paper did not allow for the evaluation of the single FI alone), and if the paper was a review or case study. Book chapters and conference abstracts were also excluded.

Search Strategy

Electronic searches. An electronic database search of Embase (1980 – 2016 week 41), Ovid MEDLINE® (1946 – September week 4 2016) and PsycINFO (1806 – October week 1 2016) was conducted. The following search terms were applied: (schiz* OR bipolar OR psycho*3) AND (family intervention* OR family therap*) and searched for within abstracts. The search was restricted to journal articles but not limited by date. Duplicates were removed and eligibility criteria were adopted to screen papers by title, abstract and full text. Papers that did not meet inclusion criteria were excluded at the relevant stage. Papers eligible at the full text stage were excluded if they were not available in the English language.

Grey literature. While seeking papers published in a peer reviewed journal aimed to reduce researcher bias and provide a greater level of paper quality, it is acknowledged that this risks publication bias. Doctoral theses and unpublished papers were therefore also sought. Relevant Doctoral theses were searched through

the electronic database Proquest Dissertations and Theses (1997 - week 41 2016).

Search terms were used as above and the search was limited to full texts. The search was not limited by date.

Correspondence. Three researchers in the area were contacted with the aim of identifying ongoing or unpublished research.

Hand searches. Reference lists of eligible papers were searched and eligible papers were also searched for in “Google Scholar” to enable identification of studies that had cited them. The reference list for the Lobban et al. (2013) review was also screened for papers meeting eligibility criteria.

Data Collection and Analysis

Study selection. Studies were selected using the outlined criteria and data was extracted using a data collection form at the full text stage.

Quality assessment. Quality assessment criteria (Appendix B) were generated in view of recommendations by the Centre for Reviews and Dissemination (CRD) Guidance (CRD, 2009) and were informed by the checklist for measuring quality for randomised and non-randomised studies (Downs & Black, 1998) and checklists developed by SIGN (2015). Criteria were graded using a similar system to that developed by SIGN and individualised grading definitions were outlined for each criterion. Whilst points were awarded in relation to fulfilment of each criterion, a total was not generated given that criteria were not equally weighted and that such scoring can lead to misrepresentation of paper quality (CRD, 2009). With the aim of assessing the quality of studies as opposed to the details reported, any information not reported in the paper was sought from the study author(s) providing that it was published within the last 10 years. Where other papers were cited for information,

these papers were accessed and the relevant details were sought. In cases where information was not reported and could not be obtained otherwise, the appropriate grading definition was selected. The quality assessment tool was piloted on five papers by two individual assessors to ensure validity. Disagreements in quality ratings were resolved through discussion and quality criteria were amended and/or clarified in light of these. A further three papers were audited and inter-rater agreement on all eight papers was calculated using Cohen's Kappa. A kappa score of 0.83 was obtained. Although according to McGinn et al. (2004), this indicates an 'almost perfect' level of agreement, it is acknowledged that the inter-rater reliability may be inflated due to final ratings of the first five papers being based on an initial discussion between assessors.

Data synthesis. Given the exploratory nature of the review question and the fact that the inclusion criteria lends itself to accruing a relatively heterogeneous sample of studies and outcomes, the results were synthesised and summarised qualitatively. In order to explore which family outcomes were assessed, these were extracted from each study and grouped under relevant category headings. Categories were screened by two individual assessors to ensure face validity.

Results

Description of Studies

Search results. The electronic search yielded a total of 2390 records. Following deduplication, 1446 remained. Titles were screened and 878 records were excluded at this stage. 568 abstracts were reviewed and a further 522 records were excluded. 46 full texts were then reviewed and a final 24 papers were excluded. Reasons included: Full texts being unavailable in the English language (n = 9); the

intervention being delivered over fewer than 10 sessions ($n = 8$); the intervention excluding the family member with psychosis ($n = 3$); the intervention including a MFT component (and having no method of controlling for this) ($n = 3$); and the intervention failing to include post intervention data for family members ($n = 1$).

Although 24 papers were excluded, several reported outcomes relating to the same study meaning that a total of 19 studies were excluded. 22 papers remained. A reference list and “cited-by” search (in “Google Scholar”) was carried out with all 22 papers and a further article was identified (Magliano et al., 2005, identified in the reference list of Magliano, Fiorillo, Malangone, Corrado De Rosa, & Maj, 2006). The reference list for the Lobban et al. (2013) review revealed two previously unidentified papers (Nugter, Dingemans, van der Does, Linszen, & Gersons, 1997; Tarrier et al., 1988). A database search of ProQuest Dissertations and Theses identified one eligible article (Suro, 2014). No further studies were identified through the cited-by search or through contacting relevant authors. A total of 26 papers met inclusion criteria for the review. Nine papers reported outcomes over four studies and were therefore grouped accordingly and assessed for quality jointly. Leff et al. (1990) reported follow up data for Leff et al. (1989). Falloon and Pederson (1985); Doane, Falloon, Goldstein, and Mintz (1985); and Doane, Goldstein, Miklowitz, and Falloon (1986) reported outcomes from the same study, as did Girón et al. (2010, 2015) and Suro (2014) and Weisman de Mamani and Suro (2016). A total of 21 studies were therefore included. Figure 1 indicates the number of papers excluded at each stage of the literature search. References for papers excluded at the full text stage are outlined in Appendix C and a summary of abstracts is presented for non-English studies.

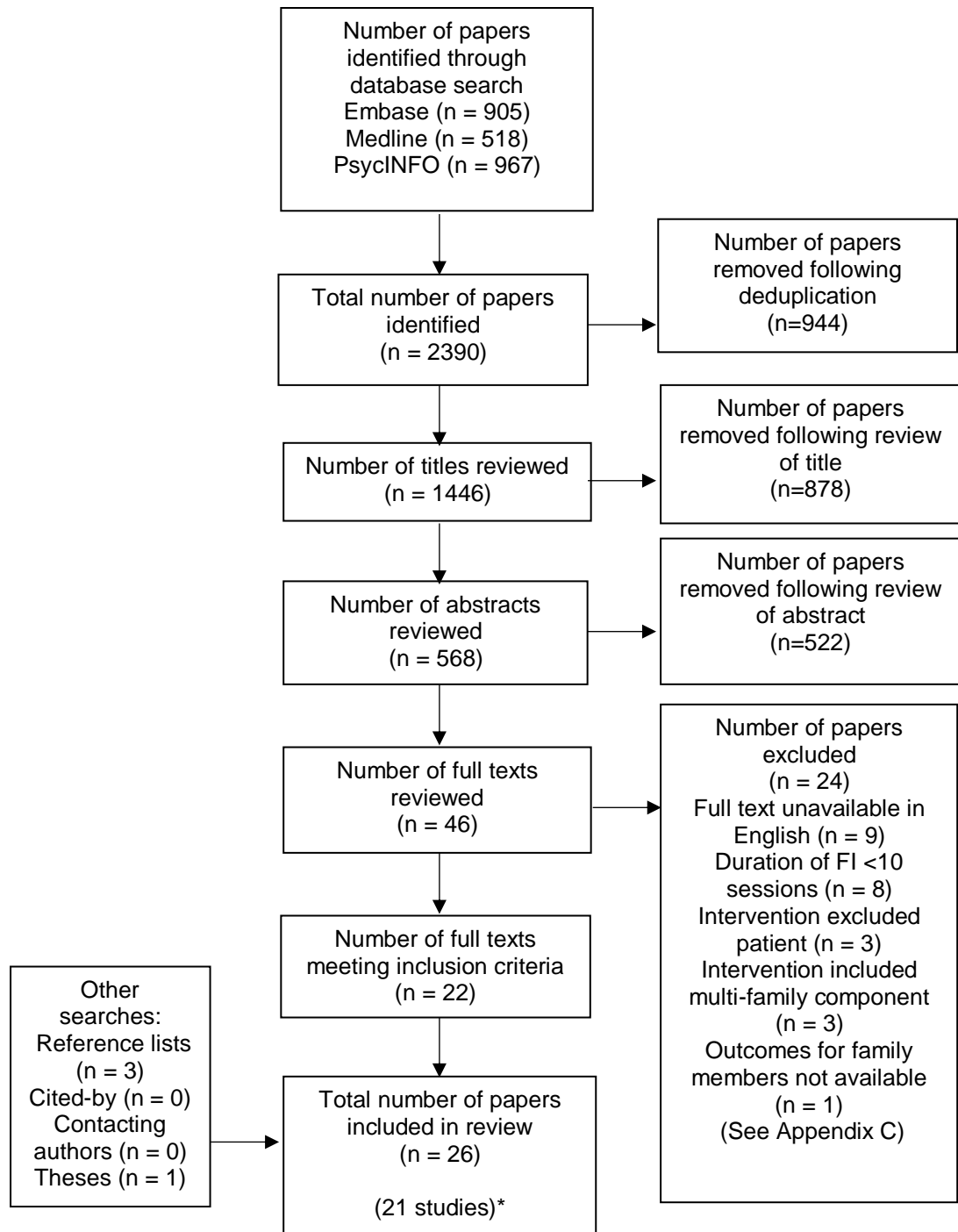


Figure 1.1. Flowchart indicating number of papers excluded at each stage of the search process.

* Although 26 papers were included, nine of these papers reported outcomes over four studies, thus, a total of 21 studies were included. Leff *et al.* (1990) reported follow up data for Leff *et al.* (1989). Falloon and Pederson (1985); Doane, Falloon, Goldstein, and Mintz (1985); and Doane, Goldstein, Miklowitz, and Falloon (1986) reported outcomes from the same study, as did Girón *et al.* (2010, 2015) and Suro (2014) and Weisman de Mamani and Suro (2016).

Included studies. Included studies were conducted between 1985 and 2016. 12 studies were carried out in Europe (UK, n = 3; Italy, n = 3; Spain, n = 3; Netherlands, n = 2; Sweden, n = 1), six in USA and the other three were conducted in Australia, Malaysia and Canada. Study characteristics are presented in Table 1.1.

Design. Three studies adopted a quasi-experimental (pre-post, single group) design. One was a controlled trial (adopting a waiting list control) and the remaining 17 were RCTs. Of these, 11 included an active control group, four included a *treatment as usual* (TAU) control, one included a waiting list control and one study recruited both an active and TAU control.

Participants. Studies predominantly included family members of those with a diagnosis of schizophrenia or schizophrenia-type disorders (n = 17). One (Fiorillo et al., 2015) recruited family members of those with a diagnosis of bipolar 1 disorder and three (Gleeson et al., 2010; Lenior, Dingemans, Schene, Hart, & Linszen, 2002; Nugter et al., 1997) included family members of those experiencing a first episode of psychosis. Those with experience of psychosis were aged between 15 and 65 years. Studies included a total of 1678 family members. Six studies provided family data from parents only, 11 included data from multiple family members and four studies failed to include information about family members. Of those that provided information, all 17 studies included parents, 11 included siblings, nine included spouses / partners, six included adult offspring, three included grandparents and five studies included “other” individuals.

Interventions. Eight studies evaluated Behavioural Family Therapy/Behavioural Family Management for Schizophrenia (Falloon, 1985) and a further two adapted this model to accommodate cultural and diagnostic factors

(Fiorillo et al., 2015; Razali et al., 2000). Two studies evaluated Applied Family Management (based on Falloon, 1985, but also includes a MFT component). Three studies evaluated interventions based on Kuipers et al. (1992, 2002) Family Work Model and six delivered alternative models: Focal Family Therapy (as outlined in Levene, Newman, & Jefferies, 1990); Educational Family Therapy (treatment manual cited in Mueser, Gingerich, & Rosenthal, 1994); Culturally Informed Therapy for Schizophrenia (Weisman de Mamani, Duarte, Koneru, & Wasserman, 2006); Relapse Prevention Therapy (Gleeson et al., 2010) and FIs based on Anderson, Reiss, and Hogarty (1986) (Leff et al., 1989, 1990) and Barrowclough and Tarrier (1987) (Tarrier et al., 1988). Four studies included single FIs (that met criteria for inclusion in this review) as active controls. These therefore provided data with regard to the efficacy of both interventions compared to one another and over time. Razali et al. (2000) adopted BFT as a control and Berglund, Vahlne, and Edman (2003); Levene, Newman, and Jefferies (1989); and Zastowny, Lehman, Cole, and Kane (1992) employed FIs incorporating psychoeducation (Conventional Family Support, Supportive Management Counselling and Supportive Family Management, respectively).

Outcomes. Outcome measures are discussed in detail below. Briefly, 33 outcome measures were used to assess 18 family outcomes across the 21 studies. Six studies measured one outcome and the remaining 15 measured more than one family outcome. Follow-up data was provided for seven studies (Falloon & Pederson, 1985; Gleeson et al., 2010; Leff, Sharpley, Chisholm, Bell, & Gamble, 2001; Lenior et al., 2002; Mueser et al., 2001; Tomás et al., 2012; Zastowny et al., 1992).

Table 1.1

Study Characteristics

Study <i>Country</i>	Design (control: <i>active control intervention</i>)	Designation of family members included N	Intervention Number of sessions delivered	Follow-up	Family outcomes (primary/ secondary)	Key findings for family members (over time) <i>Significance level:</i> ** $p < 0.01$; * $p < 0.05$ (effect size) ¹	Key findings for family members (comparison between groups) <i>Significance level:</i> ** $p < 0.01$; * $p < 0.05$ (effect size) ¹
Bellack, Haas, Schooler, & Flory, (2000) <i>USA</i>	RCT (active: <i>SFMm</i>)	Parents 77	AFM 32 sessions	Post intervention	Communication, problem solving (primary ²)	No sig. main effect of time.	No sig. main effect of AFM vs. SFMm.
Berglund et al. (2003) <i>Sweden</i>	RCT (active: <i>CFS</i>)	NR 31	BFT 10-15 sessions	Post intervention	Burden, attitude towards caring (primary)	NR	Burden: Sig. diff. between groups at discharge (in favour of BFT)**. Attitude: Sig. diff. between groups at discharge (in favour of BFT)**.
Falloon & Pederson (1985) Doane et al. (1985, 1986) <i>USA</i>	RCT (active: <i>individual management & family support</i>)	Parents 56 (36 households) (Doane et al., 1985; Falloon & Pederson, 1985) 33 households (Doane et al., 1986)	BFM 25 sessions	Post intervention, 12m. & 24m.	Mental health, social functioning, burden, coping, affective style, problem solving (primary)	Mental health (post intervention): Reduction in some symptoms in mothers in BFM (trend less evident in fathers – statistical analysis NR). Social functioning (post intervention): No sig. diff. over time. Burden: NR.	Mental Health: NR. Social functioning (post intervention): No sig. diff. between groups. Burden (subjective): Sig. diff. between groups at end of intervention & 24m. follow up** (in favour of BFM).

						<p>Coping: Increased in BFM, decreased in control at 9m. (statistical analysis NR). Affective style (12m.): Sig. increase in negative communication in control group*. No sig. diff. over time in BFM. Problem solving: NR.</p>	<p>Coping: Sig. diff at end of intervention & 24m. follow up** (in favour of BFM). Affective style (12m.): Sig diff. in negative communication in favour of BFM **. Problem solving (12m.): Sig. diff. between groups * (in favour of BFM).</p>
<p>Fiorillo et al. (2015) <i>Italy</i></p>	<p>Controlled trial (waiting list)</p>	<p>Parents, spouse/partner, sibling, offspring, other 155</p>	<p>PFI 12-18 sessions</p>	<p>Post intervention</p>	<p>Burden, perceived support (secondary)</p>	<p>PFI: Burden: Sig. improvement * (d = 0.16) in objective burden. Sig. improvement ** (d = 0.36) in subjective burden. Perceived professional support: Sig. improvement** (d = 0.78).</p>	<p>Sig. diff. between groups (in favour of PFI) for: Objective burden* (g = 0.33); subjective burden** (g = 0.55); perceived support** (g = 0.53); & help in emergencies** (g = 0.33).</p>
<p>Girón et al. (2010, 2015) <i>Spain</i></p>	<p>RCT (TAU)</p>	<p>NR 50</p>	<p>Kuipers et al. (2002) Family Work 33 sessions</p>	<p>Post intervention</p>	<p>Burden, family attitude (secondary)</p>	<p>Compared mean change scores over time. Reported in consecutive column.</p>	<p>Burden (relating to presence of patient at home): Sig. diff. between mean change scores in favour of FI* ($\Delta = 0.69$). Family attitude: Sig. diff. between mean change scores for guilt* (d = 0.71), dominance* (d = 0.71) (reduced) & empathy* (d = 0.69) (increased).</p>
<p>Gleeson et al. (2010) <i>Australia</i></p>	<p>RCT (TAU)</p>	<p>Parents, spouse, sibling, grandparents 63</p>	<p>Relapse Prevention Therapy Delivered over 7 months (no.</p>	<p>Post intervention, 12, 18, 24 & 30m.</p>	<p>Appraisal of caregiving, EE, psychological distress (primary)</p>	<p>Both groups: ECI: Sig. effect over time for aspects of experience of caregiving*. EE: Sig. reduction in EOI over time (baseline – all time points)*.</p>	<p>ECI: Significantly higher mean scores for FI on aspects of ECI across all time points: Positive personal experiences* & overall positive score*. Significantly greater reduction in appraisal</p>

			of sessions NR)			Psychological distress: No sig. diff. over time.	relating to negative symptoms across 0-18m.* & 0-24m.* EE: No sig. diff. Psychological distress: No sig. diff.
Leff et al. (1989, 1990) <i>UK</i>	RCT (active: <i>relatives group</i>)	Parents, spouse, sibling 32	FI based on Anderson et al. (1986) 0-9m.: median = 17 sessions 9-24m: median = 12 sessions	Post intervention	EE (secondary)	EE (from high to low): Sig. reduction* (both groups) at 24m.; sig. reduction in critical comments at 9m.* (both groups); sig. increase in warmth* (both groups); sig. reduction in hostility at 9m.* (relatives group); no sig. diff. in EOI.	EE: Critical comments (no sig. diff. between groups at 9m.); warmth, hostility, EOI & overall EE NR.
Leff et al. (2001) <i>UK</i>	RCT (TAU)	Parents, grandparents, spouse, sibling 34	Kuipers et al. (1992) Family Work 12 sessions	12m.	Burden, knowledge, EE (secondary)	Burden: Sig. reduction in both groups* (exp: d = 0.52; control: d = 0.60). Knowledge: No sig. diff. EE: Sig increase in warmth* (d = 0.85) & decrease in critical comments* (d = 0.93) in FI.	Burden: NR. Knowledge: No sig. diff. EE (critical comments): Sig. greater reduction in FI compared to TAU at 12m.*
Lenior et al. (2002) <i>Netherlands</i>	RCT (TAU)	Parents 63	BFM 18 sessions	Post intervention & 1 st follow up: mean of 34m. 2 nd follow up: mean of 8 years.	EE (primary)	EE: Sig. effect over time* (overall EE – both groups), EE reduced at 1 st follow up & increased at the 2 nd ; sig. reduction in criticism at 1 st follow up* (both groups); sig. effect over time for EOI** (FI: Reduced at 1 st follow up & increased at the 2 nd . TAU: EOI increased at the 1 st follow up & reduced at the 2 nd).	EE: No overall intervention effect for overall EE; sig. diff. in course of EOI for each group*.

Levene et al. (1989) <i>Canada</i>	RCT (active: SMC)	Parents 10	FFT 28 sessions (approx.)	Post intervention	Family functioning (secondary ²)	No sig. diff. over time in either intervention.	No sig. treatment effect.
Magliano et al. (2005) <i>Italy</i>	Quasi-experimental, pre & post single group	Parents, spouse, sibling, offspring, other 118	BFM Delivered over 1 year (no. of sessions NR).	Post intervention	Burden, coping, perceived support (secondary ²)	Burden: Sig. reduction in objective burden** (d = 0.53) & subjective burden** (d = 0.60). Coping: Sig. increase in coping on majority of components within scale* (d = 0.24-0.67). Support: Sig. increase in perceived professional help** (d = 0.59).	NA
Magliano et al. (2006) <i>Italy</i>	RCT (waiting list)	Parents, spouse, sibling, offspring, other 126	BFM At least 18 sessions	Post intervention	Burden, perceived support, social resources (secondary)	Burden: Objective family burden sig. improved in both groups (exp*: d = 0.15; control*: d = 0.46). Subjective burden, sig. increase in both groups (exp**: d = 0.33; control**: d = 0.36). Support & social resources: Sig. increase in social contacts* (d = 0.36), social help* (d = 0.25) & perception of professional support** (d = 0.60) in BFM. Sig. increase in social support in control* (d = 0.38).	NR
Montero et al. (2001) <i>Spain</i>	RCT (active: relatives group)	NR 87	BFT 33 sessions (approx.)	Post intervention	Psychological distress, EE, knowledge (secondary ²)	Psychological distress: No sig. reduction in either group. EE: Sig. reduction overall for both groups (BFT**; relatives group*). Sig. reduction in critical	NR

						comments* & increase in positive comments* & EOI** for BFT. Knowledge: Sig. increase (BFT** ($\Delta = 1.23$), relatives group** ($\Delta = 1.22$)).	
Mueser et al. (1994) <i>USA</i>	Pilot study: Quasi-experimental, pre & post single group	Parents, sibling, offspring 30	EFT 20-33 sessions	Post intervention	Burden, knowledge (primary ²)	Burden: Reduction (statistical analysis not conducted). Knowledge: Sig. improvement in knowledge** (d = 1.68).	NA
Mueser et al. (2001) <i>USA</i>	RCT (active: <i>SFMm</i>)	Parents, sibling, other 280	AFM 29 sessions (approx.)	Post intervention & 24m.	Family attitude, burden (secondary ²)	Attitude: No sig. diff. in attitude over time (both groups). Burden: No sig. diff. in burden over time (both groups).	Attitude: AFM associated with significantly lower levels of rejecting attitudes than SFMm** (d = 0.31 & d = 0.30 reported at end of intervention & follow up, respectively). Burden: No sig. diff. between groups.
Nugter et al. (1997) <i>Netherlands</i>	RCT (active: <i>individual treatment & psycho-education</i>)	Parents 91	BFM 18 sessions	Post intervention	EE (primary ²)	No sig. diff. over time in either group.	No sig. diff. between groups.
Razali et al. (2000) <i>Malaysia</i>	RCT (active: <i>BFT</i>)	NR 143	CMFT 11 sessions (approx.)	Post intervention	Burden (secondary ²)	NR	Burden significantly lower in CMFT at 12m.* (g = 0.40).

Suro (2014); Weisman de Mamani & Suro (2016)	RCT (active: <i>psycho-education</i>)	Parents, partner, sibling, offspring, grandparents, other	CIT-S 15 sessions	Post intervention	Burden, interdependence shame, guilt (primary)	Burden: Sig. reduction in CIT-S** & control*. Interdependence: NR. Shame: Sig. reduction in CIT-S** & control*. Guilt: Sig. reduction CIT-S**, NSD in control.	Burden: Sig. improvement in CIT-S compared to control**. Interdependence: No sig. diff. Shame: No sig. diff. Guilt: Sig. improvement in CIT-S compared to control*.
USA		113					
Tarrier et al. (1988)	RCT (TAU & <i>education</i>)	Parents, spouse, sibling, offspring	Behavioural intervention (symbolic & enactive) ³	Post intervention	EE (secondary)	FI: Sig. reduction in relatives rated as 'high EE' from baseline – 9m. (symbolic* & enactive**). When symbolic & enactive FI combined, for relatives rated as 'high EE' at baseline, sig. reduction in critical comments**, EOI** & increase in warmth**. TAU & active control combined: For relatives rated as 'high EE' at baseline, sig. reduction in critical comments**. For those rated as low EE at baseline, sig. increase in critical comments**.	At 9m.: Combined FI (symbolic & enactive) revealed significantly fewer relatives rated as 'high EE' compared to controls (active & TAU)*(OR = 4.29) & sig. reduction in critical comments compared to controls (active & TAU)*.
UK		46	13 sessions				
Tomás et al. (2012)	Quasi-experimental, pre, post & follow-up	Parents, partner, sibling	Kuipers et al. (2002) Family Work	Post intervention & 6m.	Burden, quality of life, EE (secondary ²)	Burden: From baseline to 6m. follow-up: Sig. decrease in 4/7 areas* measured. Quality of life: Sig. increase in 2/6 areas*. Sig. increase in 3/6 areas from end of intervention to 6m. follow up*. EE: Sig. reduction in 1/3 areas (criticism**).	NA
Spain		35	11 sessions minimum				

Zastowny et al. (1992)	RCT (active: SFM)	Parents 38	BFM 16 sessions	Post intervention, 6m. & 12m.	Communication, problem solving, knowledge, family climate (conflict), burden, EE, awareness of community resources (secondary ²)	Both groups: Sig. impact on elements of communication*, problem solving*; knowledge**, family climate (conflict)**, burden*, awareness of resources**. Sig. reduction in 2/3 elements of EE (warmth* & critical comments*).	No specific effects for BFM.
USA							

Note. Abbreviations:

RCT = Randomised Controlled Trial; Sig. = Significant; NR = Not reported; Diff. = Difference; d = Cohen's d; g = Hedges g; FI = Family Intervention; Δ = Glass' delta; EE = Expressed Emotion; ECI = Experience of Caregiving Inventory; EOI = Emotional over Involvement; Exp. = Experimental; NA = Not Applicable; OR = Odds Ratio.

Intervention abbreviations (listed alphabetically):

AFM:	Applied Family Management (modelled on BFT, Falloon, 1985) (+ MFT)
BFT/BFM:	Behavioural Family Therapy/Behavioural Family Management (Falloon, 1985)
CFS:	Conventional Family Support (family psychoeducation) (Tarrier et al., 1988)
CIT-S:	Culturally-Informed Therapy for Schizophrenia (Weisman de Mamani et al., 2006)
CMFT:	Culturally Modified Family Therapy (Razali et al., 2000)
EFT:	Educational Family Therapy (psychoeducation) (treatment manual cited in Mueser et al., 1994)
FFT:	Focal Family Therapy (psychodynamic model) (as described in Levene et al., 1990)
PFI:	Psychoeducational FI (adapted from Falloon (1985) for Bipolar 1 Disorder & Italian setting) (Fiorillo et al., 2015)
SFM:	Supportive Family Management (family psychoeducation) (outlined in Zastowny et al., 1992)
SFMm:	SFM (+ multi-family support group) (outlined in Bellack et al., 2000; Mueser et al., 2001)
SMC:	Supportive Management Counselling (integration of psychoeducation models) (outlined in Levene et al., 1989)

¹In the absence of effect sizes reported in papers, these were calculated by the reviewer (providing a sufficient amount information was available to do so). In accordance with The Cochrane Collaboration (2011) the standardised mean difference was calculated for continuous outcomes (d, Δ & g where appropriate) and the odds ratio (OR) was calculated for dichotomous data.

²Family outcomes were measured alongside other outcomes and the primary outcome was not specified. Given this, a judgement was made based on the perceived priority of outcomes listed in the study.

³Symbolic FI incorporated skills taught through discussion and instruction. Enactive FI taught skills through participation and action i.e. role play (FI based on Barrowclough & Tarrier, 1987).

Quality of Studies

Confounding variables. Given the differences in measured outcomes, there was a great deal of variability in potential confounding factors. The majority of studies (17/21) presented information about possible confounders, including sociodemographic information, type, severity and length of illness, frequency of contact, age, gender and engagement with other treatments. Despite this, only nine studies indicated how potential confounders had been assessed or allowed for within analyses. It is also noted that as family outcomes were often not the primary focus of studies, confounding variables relating to the individual with psychosis as opposed to family outcomes were primarily reported in these studies.

Comparison groups & blinding. Where comparison groups were adopted ($n = 18$), participants were randomised to conditions in all but one study (Fiorillo et al., 2015). Nine studies adopted methods to blind assessors from measured outcomes. Control groups included TAU, waiting list and active groups. There was very little consensus across studies with regard to the level of input provided within these groups which led to a great deal of variation within groups. TAU and waiting list groups varied from medication only to medication + multi-disciplinary input + family support and psychoeducation; the latter therefore providing a much more rigorous test of the unique contribution of the FI. Likewise, active controls varied from individual therapy to MFT to single FIs that met inclusion criteria for this review. Where single FIs were delivered as controls ($n = 4$), while these studies shed light on data from two FIs of interest to this review, it was not possible to establish the extent to which changes in outcomes could be attributed to FI due to a lack of TAU/waiting list conditions. Furthermore, it is noted that two RCTs failed to report

comparative analyses on outcomes relating to this review (Magliano et al., 2006; Montero et al., 2001). While these studies shed light on pre and post data for both conditions, a lack of comparative analyses prevents exploration of whether outcomes for FIs remain significantly different to controls.

Attrition. Overall, attrition rates (from baseline to end of intervention) were relatively high and only seven studies (Bellack et al., 2000; Berglund et al., 2003; Falloon & Pederson, 1985/Doane et al., 1985, 1986; Fiorillo et al., 2015; Girón et al., 2010, 2015; Nugter et al., 1997; Tarrier et al., 1988) either achieved no drop-out or attrition was less than 20% and managed through appropriate analyses. In three studies, attrition was greater than 20% and not taken into account with regard to analyses. Seven studies reported reasons for drop-out. These included exacerbation or improvement of symptoms (for the affected family member), physical or mental health problems relating to other family members and a lack of interest or engagement from both parties.

Follow-up. Data was only considered as follow-up if it was collected following a period of time after the intervention had ended. Seven studies met this criteria, shedding some light on the longer term impact of FIs, although one study (Zastowny et al., 1992) did include booster sessions within this period. Four studies considered attrition at follow-up within analyses (where necessary).

Power, sample size and analyses. Assessment regarding adequacy of sample size was informed by retrospective power calculations by the reviewer. Thirteen studies were considered adequately powered to a medium effect size. None of these studies detailed a priori power analyses to determine sample size. The lack of adequate sample sizes also impacted on statistical analyses, with some studies using

inappropriate analyses and statistical tests intended for larger samples. The majority of studies failed to report effect sizes for outcomes relevant to this review. These were therefore calculated by the reviewer (where information was available). While this aimed to better establish the extent of the impact of interventions, small sample sizes are likely to lead to inflation of effect sizes (Slavin & Smith, 2009). It is also noted that non-randomised designs may produce larger effect estimates (The Cochrane Collaboration, 2011). The need to exercise caution when interpreting effect sizes where sample sizes are small and not randomised is therefore acknowledged.

Validity of intervention. Generally, FIs were manualised and/or followed a validated model. Only eleven studies considered fidelity in the format of regular supervision and discussion of family work. Of these, three adopted a formal fidelity measure. Mueser et al. (1994) developed a measure to evaluate therapist fidelity to EFT and BFT and Mueser et al. (2001) adopted a fidelity measure for BFT (Falloon, McGill, Matthews, Keith, & Schooler, 1996). Weisman de Mamani & Suro (2016) adopted the CIT-S Therapist Competency Adherence Scale (Weisman et al., 1998; 2002) to evaluate fidelity to CIT-S. A further two studies video/audio taped sessions for review (Girón et al., 2010, 2015; Zastowny et al., 1992) but details of fidelity measures were not provided. In light of the overall lack of consideration regarding fidelity, it remains difficult to ascertain how closely FIs were adhered to. Samples were most frequently obtained from in-patient settings or community mental health teams, suggesting that they were representative of the population.

Scores on the quality assessment criteria are outlined in Table 1.2. The quality of studies in relation to outcome measures and family characteristics are discussed in the context of review questions and are outlined below. Although

differences in the quality of evidence according to study design are acknowledged, findings from both randomised and non-randomised studies are discussed concurrently. This allows for the summary and exploration of outcome measures used regardless of study design. Furthermore, due to the limited number of non-randomised studies and variability of outcomes measured, it is difficult to draw meaningful conclusions through summarising evidence separately. Where relevant, the possible impact of design issues on outcomes are discussed in relation to evidence outlined on a case by case basis.

Summary of Findings

Family outcomes measured and impact of interventions based on these outcomes. 18 family outcomes were measured across the 21 studies. Family outcomes were the primary focus in eight studies. It is acknowledged that ten studies failed to indicate primary outcomes, thus having implications for quality assessment and interpretation of findings. As outlined by Andrade (2015), failure to report a priori primary outcomes runs the risk of researchers selecting main outcomes based on significant findings and makes the calculation of sample size problematic. The risk of yielding false positive and negative errors from secondary outcomes is also considered. Outcomes are summarised under five main headings: *Wellbeing, Family interactions, Knowledge and skills, Support, and Experience of caregiving*. 86% (n = 18) of studies reported a positive impact of FIs on at least one outcome. Categories, outcomes and outcome measures are listed in Table 1.3 and the impact of FIs based on these outcomes is discussed.

Table 1.2

A Summary of Study Quality as Rated Using the Quality Assessment Tool Developed for the Purpose of this Review.

Study	Quality Assessment Criteria (see Appendix B for definition of each criterion and associated ratings)												
	1. Confounding variables	2. Comparison	3. Blinding	4. Drop-out	5. Clear aims	6. Outcome measures systematically delivered	7. Outcome measures develop- mentally appropriate	8. Follow-up	9. Appropriate analyses	10. Power & sample size	11. Replicability	12. Family member information	13. Intervention representative of routinely delivered
Bellack et al. (2000)	2	2	0	2	2	2	0	0	2	1	1	1	2
Berglund et al. (2003)	1	1	0	2	2	1	0	0	1	1	2	0	1
Falloon & Pederson (1985); Doane et al. (1985, 1986)	1	2	2	2	1	1	0	2	1	0	1	2	2
Fiorillo et al. (2015)	1	1	0	2	2	2	0	0	2	1	1	2	2
Girón et al. (2010, 2015)	2	2	2	2	2	2	0	0	1	0	2	0	2
Gleeson et al. (2010)	2	2	2	1	2	2	0	2	2	1	2	1	1
Leff et al. (1989, 1990)	1	2	2	1	1	2	0	0	1	1	0	1	1
Leff et al. (2001)	2	2	2	0	1	1	0	1	1	1	1	1	2
Lenior et al. (2002)	2	2	0	1	2	2	0	2	1	0	1	1	1
Levene et al. (1989)	1	1	0	1	2	2	0	0	0	0	1	1	1
Magliano et al. (2005)	0	0	0	1	2	2	0	0	0	1	2	1	2
Magliano et al. (2006)	2	2	0	1	2	2	0	0	1	1	2	2	2
Montero et al. (2001)	2	2	2	1	2	2	0	0	1	1	2	0	2
Mueser et al. (1994)	0	0	0	1	2	1	0	0	0	0	2	1	1
Mueser et al. (2001)	2	2	0	1	2	1	0	2	2	1	2	1	2
Nugter et al. (1997)	1	2	0	2	2	2	0	0	2	0	1	1	1
Razali et al. (2000)	1	1	2	0	2	0	0	0	2	1	1	0	1
Suro (2014); Weisman de Mamani & Suro (2016)	2	2	0	1	2	2	0	0	2	1	2	2	2
Tarrier et al. (1988)	0	2	2	2	2	2	0	0	1	0	1	1	1
Tomás et al. (2012)	0	0	0	0	2	2	0	1	2	1	2	2	2
Zastowny et al. (1992)	1	1	2	1	2	1	0	1	1	0	2	1	1

Table 1.3

Measures Used to Assess Outcomes (Listed by Category) (n = Number of Studies).

Note: Several studies measure more than one outcome within the same category.

Category (n)	Outcome (n)	Outcome measures adopted (n) (See Appendix D for Author(s), date & full reference)	Are outcome measures considered valid &/or reliable based on independent assessment of psychometric properties?*(Y = Yes / N = No)
Wellbeing (15)	Burden (13)	The Subjective Distress Scale (1)	N
		Family Problems Questionnaire (3)	Y
		Family Burden Interview (2)	Y
		Social Adjustment Scale (modified) (2)	N
		Social Behaviour Assessment Scale (3)	Y
		Assessment of Burden Interview (1)	N
		Burden Assessment Scale (1)	Y
	Psychological distress (including mental health/psychological symptoms, guilt & shame) (4)	General Health Questionnaire-28 (2)	Y
		Self-conscious Emotions for Schizophrenia Scale (1)	N
		Hopkins Symptom Checklist (1)	Y
	Coping (2)	Family Coping Questionnaire (1)	Y
		Rating of verbal report (1)	N
	Quality of life (1)	World Health Organisation Quality of Life (WHOQoL)Assessment (1)	Y
	Inter-dependence (1)	Self-Conscious Emotions for Schizophrenia Scale (1)	Y
Family Interactions (13)	Expressed emotion (9)	Camberwell Family Interview (6)	Y

		Five Minute Speech Sample (2)	Y
		Family Questionnaire (1)	Y
	Family functioning (relationships) (1)	FAM-III – Dyadic Relationships Scale (1)	Y
	Family climate (conflict) (1)	Frequency of Conflict Questionnaire (1)	N
	Affective style (1)	Interaction Task (affective style categorised) (1)	Y
	Family attitude (2)	Dyadic Interaction Encounter (1)	N
		Patient Rejection Scale (1)	N
Knowledge & Skills (4)	Knowledge (4)	Knowledge Interview (1)	N
		Knowledge About Schizophrenia Inventory (1)	Y
		The Knowledge Test (1)	N
		The Mental Illness Questionnaire (1)	N
	Problem solving (3)	Interaction Task (problem solving style assessed) (1)	N
		Family Problem Discussion (1)	N
		Family Problem Solving Task (1)	Y
	Communication skills (2)	Family Problem Solving Task (1)	Y
		Family Problem Discussion (1)	N
	Perception (3)	Social Network Questionnaire (3)	Y
Support (5)	Awareness (1)	Community Resources Scale (1)	N
	Social resources/functioning (2)	Social Adjustment Scale-Self Report (1)	Y
		Social Network Questionnaire (1)	Y
Experience of Caregiving (2)	Appraisal of Caregiving (1)	Experience of Caregiving Inventory (1)	Y
	Attitude towards Caring (1)	Subjective Attitude Scale (1)	N

*Outcome measure considered valid and/or reliable based on independent assessment of psychometric properties reported in published papers.

Wellbeing. 15 studies reported outcomes relating to wellbeing and four of these reported more than one measure within this category (Falloon & Pederson, 1985; Magliano et al., 2005; Suro, 2014/Weisman de Mamani & Suro, 2016; Tomás et al., 2012). 13 studies included measures of burden, the most frequently reported family outcome. This concept covered a broad range of components including both subjective burden (emotional and psychological factors) and objective burden (environmental and behavioural factors such as routine, engagement with activities etc.). While it is acknowledged that there is some overlap between components measured within the *burden* concept and other categories, this category can be defined by family members' perceived impact of the mental illness experienced by their loved one on them. The impact of FIs on burden was measured using a variety of outcome measures. Nine studies adopted measures that demonstrate good reliability, including the Family Problems Questionnaire (Morosini, Roncone, Veltro, Palomba, & Casacchia, 1991) which demonstrates good test –re-test reliability (Magliano et al., 1998), the Social Behaviour Assessment Scale (Platt, Weyman, Hirsch, & Hewett, 1980), the Family Burden Interview (Pai & Kapur, 1981) and the Burden Assessment Scale (Reinhard & Horwitz, 1994). The remaining four studies failed to adopt reliable and valid measures of burden, potentially adding uncertainty to the actual concept being measured. Despite this, the vast majority of studies (12/13) indicated a significant impact of FIs on burden. Three were quasi-experimental (pre-post, single group) designs (Magliano et al., 2005; Mueser et al., 1994; Tomás et al., 2012). Magliano et al. (2005) reported a significant reduction with a medium effect size, Tomás et al. (2012) reported burden to reduce in 4/7 areas measured and although Mueser et al. (1994) reported a reduction in burden,

statistical analyses were not included. The remaining nine studies were controlled trials. Six reported significant benefits of FIs when compared with controls. Small-medium effect sizes were calculated for two RCTs (Girón et al., 2010; Razali et al., 2000) and one controlled trial (Fiorillo et al., 2015). In addition to comparative analyses, two RCTs (Weisman de Mamani & Suro, 2016; Zastowny et al., 1992) revealed a significant reduction in both active and control conditions. Weisman de Mamani & Suro (2016) delivered psychoeducation within the control group and the FI delivered within the control group for Zastowny et al. (1992) met inclusion criteria for this review. Two failed to provide comparative analyses but indicated improvements in both conditions, again with small-medium effects (Leff et al., 2001; Magliano et al., 2006).

Burden was measured at follow-up in four studies (Falloon & Pederson, 1985; Leff et al., 2001; Tomás et al., 2012; Zastowny et al., 1992) and results indicate that positive effects were maintained at up to 24 months following intervention; suggesting that FIs can be effective in sustaining a reduction in family burden. Mueser et al. (2001) was the only study measuring burden that did not report a reduction. It is noted that Mueser et al. compared BFT and MFT to MFT alone and found no significant reduction in burden over time or between interventions. It may be that BFT adds nothing above MFT with regard to reducing burden; however, Mueser et al. did not adopt a specific assessment of family burden but rather measured burden using the Social Adjustment Scale (Schooler, Hogarty, & Weissman, 1979, as cited in Mueser et al., 1994, 2001). Given that burden is just one component within this scale, its sensitivity as a burden measure is questionable.

Four RCTs measured psychological distress; two evaluating general distress using the GHQ-28, one measuring psychological symptoms (Falloon & Pederson, 1985) and one measuring guilt and shame specifically (Suro, 2014/Weisman de Mamani & Suro, 2016). Gleeson et al. (2010) found no significant effect of FI on psychological distress when compared to TAU. Similarly, Montero et al. (2001) reported no significant effect of FI over time. Suro (2014)/Weisman de Mamani and Suro (2016) indicated that guilt reduced significantly when FIs were compared to a psychoeducational group but there was no significant difference in shame. Although a statistical analysis was not conducted, Falloon and Pederson (1985) noted a reduction in some symptoms over time in mothers engaging in FI.

Of the two studies that measured coping, Magliano et al. (2005) reported significant improvements with a small-medium effect size pre and post FI and Falloon and Pederson (1985) indicated coping skills to be significantly better following FI when compared to a control at the end of intervention and at a 24 months follow up. Tomás et al. (2012) demonstrated a significant increase in quality of life on pre and post measures. Suro (2014) also measured the impact of FI on inter-dependence compared to a psychoeducational group, however no significant difference was found.

Overall, the literature indicates a positive impact of FIs on burden. It remains difficult to determine the impact of FIs on other wellbeing outcomes due to the limited number of studies investigating psychological distress, quality of life, and family coping. It is noteworthy that the vast majority of studies (12/15) reporting outcomes relating to wellbeing were published more recently (post year 2000).

Family interactions. Outcomes relating to family interactions were reported by 13 studies. One study, Zastowny et al. (1992) investigated two aspects of family interaction. The construct of expressed emotion was measured by nine studies and was most frequently ($n = 6$) evaluated using the Camberwell Family Interview (CFI) (Leff & Vaughn, 1985). This demonstrates concurrent and predictive validity (Hooley, 1985; Miklowitz, Goldstein, Falloon, & Doane, 1984) and measures family members' level of criticism, hostility, emotional over-involvement, warmth and positive remarks towards the service user. Two studies adopted the Five Minute Speech Sample (FMSS) (Magaña et al., 1986). The FMSS demonstrates significant overall agreement when compared to CFI and measures criticism, emotional over-involvement and positive comments. Eight of the nine studies were RCTs and one was a quasi-experimental (pre-post, single group) design (Tomás et al., 2012). Despite the historical aims of FIs in reducing expressed emotion within families, results relating to this outcome were varied. An overall reduction in EE over time was reported in four RCTs but this was only specific to the FI condition for one study (Montero et al., 2001). The other three indicated reductions in both experimental and control conditions (Leff et al., 1989, 1990; Lenior et al., 2002; Montero et al., 2001). On exploring pre and post intervention differences in individual components of EE, a reduction in critical comments and an increase in warmth was noted most frequently ($n = 4$); however, these changes were also often apparent in control conditions. Seven of the eight RCTs made comparisons to controls for at least one element of EE. Only one of the five studies comparing global EE reported a significant difference between groups (Tarrier et al., 1988); however, insufficient information was provided to enable effect size calculation. Two studies

reported significant intervention effects on one component of EE (critical comments) (Leff et al., 2001; Tarrier et al., 1988).

Although not termed as expressed emotion, other interactional styles were evaluated through five studies that reported on family functioning (and relationships), conflict, affective style and family attitude. Levene et al. (1989) used the Dyadic Relationship Scale (FAM-III) to assess relationships between family members and a questionnaire to elicit the frequency of family conflict was adopted by Zastowny et al. (1992). Levene et al. revealed no significant treatment or time effect for family relationships. Conversely, Zastowny et al. revealed family conflict to reduce over time following BFM and a FI including a psychoeducational component. Parental affective style was measured in Doane et al. (1986) and negative communication was significantly reduced in the experimental condition compared to controls 3 months post intervention. Girón et al. (2015) also reported a significant, positive impact of FI (with a medium effect) on some areas of family attitude but not others. Mueser et al. (2001) demonstrated a significant impact of FI (with a small effect) on levels of rejecting attitudes towards the patient as measured using the Patient Rejection Scale (Kreisman et al., 1988).

Overall, there is a lack of consistency with regard to results relating to family interactions. Difficulties in measuring the construct of expressed emotion are also acknowledged and it is noted that measures are not highly correlated (Hooley & Parker, 2006). Interestingly, three of the four studies that found no significant effect on global expressed emotion (compared to controls) used measures other than the CFI; mainly the FMSS which is known to “under-identify” high expressed emotion when compared to the CFI (Hooley & Parker, 2006). Studies adopting the CFI as a

measure of expressed emotion were more likely to find significant results if only on one category of the construct. It may be that the two measures are tapping in to a different construct altogether or that there is simply a high rate of measurement error between assessments. Either way, the lack of consistency in findings makes it difficult to draw firm conclusions regarding the results. While follow-up data does not reveal any sustained reduction in expressed emotion (as an entire concept), three studies do consistently report a sustained reduction in critical comments (up to 12 months) (Leff et al., 2001; Tomás et al., 2012; Zastowny et al., 1992). Given this and the reduction in negative communication and rejecting attitudes reported by Doane et al. (1986), Girón et al. (2015) and Mueser et al. (2001), it is possible that FIs are more effective at having an impact on this aspect of expressed emotion.

Alternatively, this may indicate a greater sensitivity to this factor within outcomes measuring expressed emotion. It is noted that almost 50% of studies measuring family interactions were published prior to the year 2000 and only one was published within the last five years. This perhaps demonstrates a shift in the way in which FIs are being delivered and the outcomes that are considered important.

Knowledge and skills. Family members' knowledge was assessed in four cases and findings varied. Of the RCTs, Leff et al. (2001) revealed no significant effect of FI on knowledge and two studies (Montero et al., 2001; Zastowny et al., 1992) reported a significant increase in knowledge over time for both FIs and control groups. These studies included a relatives group and another single FI as controls which may explain the increase in knowledge in both conditions. Mueser et al. (1994) reported a significant increase with a large effect size in family members' knowledge about the patient's illness following intervention and this intervention had

a particular focus on education (EFT). It is also noted that this study was a quasi-experimental (pre-post) design, possibly explaining the large effect size yielded. Given these studies lack comparative data to TAU/waiting list controls, it is not possible to establish whether increases in knowledge can be attributed solely to FIs.

Findings were mixed with regard to the impact of FIs on problem solving skills. Bellack et al. (2000) revealed no significant effect, Doane et al. (1986) indicated a significant improvement in favour of FI when comparing it to individual therapy and Zastowny et al. (1992) indicated an improvement in problem solving in two single FIs. Two studies measured communication skills and revealed no significant impact of FIs (Bellack et al, 2000; Zastowny et al., 1992). Overall, the studies indicate that FIs made little unique impact on knowledge or skills of family members, however, the number of studies investigating these factors were few, therefore it is not possible to draw any firm conclusions with regard to this.

Support. Factors relating to family members' support networks were measured across five studies: three RCTs (Falloon & Pederson, 1985; Magliano et al., 2006; Zastowny et al., 1992), one controlled trial (Fiorillo et al. 2015), and one quasi-experimental (pre-post) study (Magliano et al., 2005). A positive impact of FI on pre and post outcomes relating to perceived support were reported across three studies (Fiorillo et al., 2015; Magliano et al., 2005; Magliano et al., 2006) and improvements ranged between a small-medium effect. Zastowny et al. (1992) reported improvements in awareness of community resources in both conditions (pre and post). Only one study (Fiorillo et al., 2015) reported differences in perceived supports between groups and reported FI to be superior to a waiting list control (with a small-medium effect). Magliano et al. (2006) also reported a significant increase in

social contacts (over time) and Falloon and Pederson (1985) measured social functioning; however, there was no significant impact of FI on this outcome.

Experience of caregiving. Experience of caregiving was the least frequently measured outcome with only two studies (RCTs) reporting on family members' appraisal and attitude to caregiving (Berglund et al., 2003; Gleeson et al., 2010). Both reported FIs to have a significantly positive impact on attitudes towards caring for the affected individual when compared to a control group. Gleeson et al. (2010) also reported these effects at follow-up. While this is promising, it is not possible to make firm conclusions with regard to the impact of FIs on family members' experiences of caregiving.

Participation of family members and involvement of children and young people. Four studies failed to report any information about family members (Berglund et al., 2003; Girón et al., 2010, 2015; Montero et al., 2001; Razali et al., 2000). Of the remaining 17, data was gathered from parents (in all cases, $n = 17$), siblings ($n = 11$), partners/spouses ($n = 9$), offspring ($n = 6$), and grandparents ($n = 3$). Five studies reported data from "others" including non-immediate relatives and friends. None of the included papers made reference to children or young people or to the adaptation of interventions to make them developmentally appropriate. Most studies failed to report inclusion criteria for participating relatives, however from review of papers including offspring and siblings, there was no information to suggest that these participants were children or young people. Of the six studies that included offspring, three reported the mean age of family members to be over 50 years and two stated that family members must be over the age of 16 and 18 to take part. Mueser et al. (1994) indicated that included offspring had a diagnosis of

schizophrenia, suggesting that these were adult offspring. Furthermore, no interventions or outcome measures were adapted for use with children and young people suggesting that this population were not represented in the selected studies. Overall, there was a significant lack of information with regard to family members participating in interventions.

Discussion

Summary of Main Results

The concept of burden was the most frequently measured outcome among family members, followed by expressed emotion. Generally, studies including measures of burden were published more recently than those exploring expressed emotion. This perhaps reflects literature indicating a shift in emphasis of FIs over time, with current FIs placing a greater emphasis on family members and their wellbeing in addition to the initial aim of altering family climate. It is possible that this is a reflection of the difficulty in measuring the abstract nature of expressed emotion and/or may also be due to an increased acknowledgement of the mutual benefits of FIs to patients and their families (Mcfarlane et al., 2003). Despite this, there remains a relative lack of studies measuring outcomes associated with other aspects of family wellbeing, experiences of caregiving and quality of life. Furthermore, given the lack of carer informed measures, the development of an outcome measure in collaboration with carers and family members is likely to be of benefit. The review indicates a positive impact of FIs on family members for at least one outcome in 86% of studies. There are positive and consistent findings indicating a positive effect of FIs on burden, with studies reporting a sustained impact for up to 24 months. While fewer studies explored outcomes relating to perceived supports,

the results tentatively suggest that FIs are effective in increasing family members' awareness and perception of professional, community and social supports; however the literature base would benefit from more research in this area. Interestingly, while the initial aim of FIs focused on reducing expressed emotion, there was little consistent evidence to suggest that this is the case. Findings more robustly pointed to positive changes in one area of expressed emotion (critical comments), in which a reduction was maintained at up to 12 months. While outcome measures used to explore the concept of expressed emotion report good reliability and validity, the abstract nature of this construct makes it difficult to quantify (Hooley & Parker, 2006). The more consistent reduction in critical comments as opposed to other elements of expressed emotion may be reflective of the increased sensitivity of outcome measures to this factor. For example, the measure of critical comments is perhaps more concrete than capturing other aspects of expressed emotion such as warmth, emotional over-involvement and hostility. Furthermore, these concepts are perhaps open to a greater level of subjectivity. While the reduction in critical comments towards service users is not explicitly representative of a beneficial outcome to family members, it is possible that this may be influenced by a reduction in stress, increased communication skills and understanding. Given the lack of representation of studies measuring outcomes relating to quality of life, coping, psychological distress, skills and experience of caregiving, it remains difficult to draw firm conclusions in relation to these factors.

Although several studies failed to indicate which family members were included, outcomes focus on parents, adult siblings and partners/spouses. The review therefore highlights a clear lack of representation of children and young people. This

includes children and young people who may be involved in FIs through their role as sibling/offspring alone and those who identify themselves as young carers; the latter perhaps being of particular concern given that children with caring responsibilities often report that their role as a carer (and associated needs) are seldom recognised by health and social care professionals (Gladstone et al., 2011). No interventions were adapted for the inclusion of children and young people.

Overall Completeness and Applicability of Evidence

Given the fact that the search criteria was not limited by date, included studies allowed for a thorough review of outcome measures used for family members across a 31 year time period. This enabled the identification of changes in practice over time and the evaluation of FIs based on a wide variety of outcomes. The range of outcome measures means that several were investigated by too few studies to enable firm conclusions regarding the efficacy of FIs in eliciting change. Given the complete lack of studies including children and young people, the evidence failed to identify the impact of interventions on this population. The research base therefore provides a somewhat different picture to recommendations set out in treatment guidelines (SIGN, 2013) with regard to the inclusion of children and young people in FIs. Parsons, Abbott, McKnight, and Davies (2015) highlight that research involving children and young people can often be problematic, often as a result of lack of guidance from ethics committees and the perception of research with children and young people being “high risk”. It is therefore difficult to establish whether studies included in this review are a reflection of current practice or whether the lack of inclusion of this population is limited by the nature and challenges associated with involving children and young people in research.

Quality of Evidence

With 21 studies included in this review and data gathered from a variety of participants, this allowed for exploration of a number of outcomes relating to a range of family members. The vast majority of interventions followed a validated model and treatment manual and according to quality assessment criteria, interventions were generally representative of FIs delivered in routine clinical settings. It is acknowledged however that the lack of fidelity measures is a weakness of the review given that it is not possible to establish how closely interventions were adhered to. The lack of power analyses is also problematic as many studies were under-powered and attrition rates were also high. Despite this, the recruitment and retention of this population in research can be difficult (Gilbody, Wahlbeck, & Adams, 2002; Jørgensen et al., 2014) and this must be considered when taking into account issues relating to attrition. Generally, outcomes were systematically delivered and reliable and valid. Although 18 of the 21 studies were controlled trials, as already discussed, four of these delivered single FIs as controls and two only provided pre and post analyses, thus preventing the exploration of FIs compared to a waiting list or TAU control. This then makes it difficult to establish the extent to which changes in outcomes can be solely attributed to interventions. Changes in the way that research is conducted and reported over time and the impact of this on effect sizes is also acknowledged (Amato, 2001). This is evident within the current review, with older papers in particular being less systematic in reporting of methods. This, alongside the fact that authors were only contacted to clarify information if the paper was published within the last ten years increases the likelihood of studies being rated (perhaps artificially) poorly in consideration of quality assessment. While this is a

point worth considering with regard to interpretation of findings, it must also be taken into account that despite quality of reporting, many studies had small samples and were poorly controlled. This contributed to inflated effect sizes; a further point to be considered when interpreting significant findings with seemingly large effect sizes.

Potential Biases in the Review Process

Despite using scoping techniques in establishing appropriate terms and selecting relevant databases to search, it is acknowledged that this method alone is not likely to capture all relevant studies. The inclusion of searches of grey literature, scanning reference lists and the addition of a cited-by search in “Google Scholar” aimed to include as many relevant studies as possible. The adoption of a number of different search methods remains a strength of this review. While every effort was made to ensure inclusion of all relevant studies, it was not possible to translate articles written in languages other than English, meaning that this data was excluded from review. With the aim of establishing how the inclusion of these studies may have impacted on the current findings, the abstracts were summarised and are presented in Appendix C. Outcomes measured included: Burden; knowledge; psychological distress, stress and anxiety; EE and quality of life. While abstracts did not reveal the impact of FIs across all outcomes, positive effects on burden, quality of life and psychological distress were reported. The impact on knowledge appeared more variable. While these papers may have added strength to the current conclusions, failure to interpret them adds to the potential biases in this review. Approximately one third of studies were reviewed by a second rater with the aim of reducing external bias. All disagreements were settled through discussion and quality

criteria were amended where necessary. This aimed to promote consistency with regard to quality assessment and resulted in an ‘almost perfect’ level of agreement beyond chance. A number of papers failed to include all relevant information to enable a full assessment of quality. While efforts were made to contact authors, not all required information was made available. This was particularly problematic for older papers. Given the marked changes in reporting methods over time, earlier studies in particular did not include all necessary information to enable review. It was not considered practical to contact authors of papers published more than ten years ago given the time lapse. These papers were therefore rated on information reported, thus preventing an accurate rating of quality for some studies. Family outcomes were also often reported as secondary, thus further impacting on the extent of information reported.

In view of the range of outcomes included in studies, these were screened by two individual assessors and grouped under relevant category headings. While this enabled a meaningful summary and discussion of outcomes measured, the limitations of grouping outcomes in this way is considered. Primarily, the subjectivity of headings and groupings, and the potential for overlap between categories is acknowledged. For example, although the outcome *Coping* is included within the category of *Wellbeing* (due to the likely impact of increased coping on wellbeing), this outcome may also be placed in the category of *Knowledge and Skills* (as the ability to cope may also be conceptualised as an indication of increased skills). Similarly, it is acknowledged that the concepts of distress and wellbeing can be considered as two independent dimensions, although are categorised here as one (due to the likely impact of distress on wellbeing). Despite the limitations outlined in

grouping outcomes, the fact that categories were reviewed by two assessors aimed to reduce subjectivity. The transparency of categories is also promoted through outlining headings, outcomes and measures within Table 1.3. Although the current review includes non-randomised studies in addition to RCTs, case studies were excluded in view of guidance pertaining to the hierarchy of evidence and increased risk of bias (CRD, 2009; The Cochrane Collaboration, 2011). It is acknowledged that the inclusion of case studies may have been beneficial, particularly with regard to adding to our understanding of family members typically included in FIs and the type of outcomes gathered.

Agreements and Disagreements with Other Studies or Reviews

Similarly to Lobban et al. (2013), the majority of studies in the current review reported positive outcomes of FIs for family members in at least one outcome category. Interestingly, Sin and Norman's (2013) review reporting outcomes for family members engaging in psychoeducational interventions demonstrated consistently effective findings for an increase in knowledge and coping but no success in changing burden. Conversely, the current review indicated that FIs were effective in reducing burden but that only one of four studies investigating impact on knowledge yielded positive outcomes. While improvements in coping were noted, only two studies evaluated this factor, suggesting that there is insufficient evidence to conclude that FIs are successful in changing this. It is possible that the difference in nature of interventions reviewed in the current review and Sin and Norman accounts for these differences. Although not an aim of this review, this perhaps sheds light of the unique contribution of different elements of FIs. In line with Lobban et al., the current review highlighted a lack of adequate sample sizes, lack of clarity with

regard to controls, and a lack of pre-publication analyses. Similarly to Lobban et al. and Sin and Norman, the current review also established parents to be the most frequently included family members in interventions and children and young people to be less well represented. Although much of this literature indicated a lack of inclusion of siblings in FIs, it is noted that in the current review, siblings were the second most included group of family members in interventions. In line with Harvey et al. (2005), the current review highlights the wide range of outcomes measured within FIs. Harvey et al. indicated an importance of measuring carer outcomes in relation to identifying health needs, wellbeing and aspects of the caregiving experiences. It seems that more than ten years on there remains a lack of focus on these outcomes.

Implications for Practice

The current review indicates consistent evidence to suggest that single FIs for psychosis are effective in reducing burden for family members. Alongside evidence highlighting the efficacy of FIs for service users (Pharoah et al., 2010), this indicates benefits of the delivery of one single intervention for the potential benefit of all family members. While more research is required, there are tentative findings to suggest that FIs are successful in increasing perceived supports. Given that FIs do not aim to deliver individual therapy to family members, facilitating awareness of available supports is likely to be beneficial in prompting help-seeking and sign-posting; thus preventing family members' needs from being neglected. In light of the fact that the majority of studies highlight a positive impact of FIs on a wide range of participating family members, this emphasises the importance of including all relevant members in FIs and the potential benefits in participating. Given the lack of

representation of children and young people in studies, it is not possible to draw conclusions with regard to this population. While it is acknowledged that the majority of papers included precede current guidelines, more recent papers emphasise the lack of implementation of guidelines recommending the inclusion of offspring in FIs.

Implications for Research

Given the assessment of quality of studies, future research in this field will likely benefit from greater consideration of and controlling for confounding variables; inclusion of appropriate analyses to manage (perhaps inevitable) increased attrition rates associated with this population; the adoption of fidelity measures and valid and reliable outcome measures and the inclusion of power analyses and effect sizes. As noted by Lobban et al. (2013), given the shift towards increased family involvement more generally, study designs would benefit from taking this into account. More specifically, in order to establish the unique contribution of single FIs, future research would benefit from evaluating these against TAU conditions that are mindful and inclusive of carers and family members. Controlled trials would also benefit from better analyses of comparative outcomes as opposed to reporting only pre and post findings. While the present review reported a reduction in burden, future research will likely benefit from establishing the potential reasons associated with this, perhaps exploring the active ingredients of therapy with regard to this outcome and exploring this further through qualitative methodology. Finally, given the lack of representation of children and young people within this review, further exploration of this would be beneficial. While guidelines recommend the inclusion of offspring, it appears that this does not translate to practice. It would be prudent to further examine

why this may be the case in clinical practice through further research. Qualitative exploration of the views of children and young people and of clinicians will likely be helpful in moving forward.

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Chapter 2

“I’m like one of the main people involved in this...I’m worried about her”:

Understanding How Young People with a Parent with Experience of Psychosis (Including Bipolar Disorder) View Themselves in Relation to Their Parent’s Care

The article is written in accordance with author guidelines for Qualitative
Psychology (Appendix E)

Abstract

Although the impact of caring for and/or living with someone with experience of psychosis is well researched, there is a paucity of literature offering an understanding of the role of young people in their parent's care. Given the emphasis on community care and additional challenges associated with adolescent development, a better understanding of how young people view themselves in the context of their parent's care is important in establishing how their needs may best be met. A grounded theory approach was adopted in order to develop this. Data was gathered from 12 interviews with 11 participants (aged 14-18 years) with a parent with experience of psychosis. At the core of the provisional theory generated is how young people establish and negotiate their role in relation to their parent's care in the context of adolescence; balancing caring for and/or living with a parent with experience of psychosis with "being a teenager". This process appears very much dependent on young people's perception of parental needs and supports and among other factors, is facilitated by having appropriate information regarding presentation and management of parental psychosis (that is specific and formulation based). Young people perceiving adults to view them as "too young" appeared to be a significant barrier to this. Findings have implications for clinical practice, highlighting the role of family focused interventions, better support, appropriate information sharing and adults recognising and validating young people's experiences.

Keywords: young people, parental mental illness, psychosis, grounded theory

Introduction

Schizophrenia-type disorders and bipolar disorder are recognised as common forms of enduring mental illness. Although differences in presentation and symptoms are acknowledged, these diagnoses are associated with a certain degree of complexity and commonalities in terms of presentation and treatment experiences. These include the increased risk of hospitalisation, prevalence of self-harm and suicidal ideation, occurrence of psychotic symptoms, (often) involvement with specialist services and the increased need for systemic working, including family based approaches (Byrne, 2007; Miller, 2011; National Institute for Health and Care Excellence [NICE], 2014a, 2014b; Roth & Pilling, 2013). According to the American Psychiatric Association (2013), hallucinations, delusional beliefs, disorganised speech and/or motor behaviour and negative symptoms are common features of psychosis. Although symptoms of this nature may not always be present with bipolar disorder, the term *psychosis* is often used to describe a range of mental illnesses in which psychotic symptoms may occur and this term will be adopted here to encompass schizophrenia-type disorders and bipolar disorder.

Existing Literature Relating to Parental Mental Illness

Although the impact of living with an individual with experience of psychosis is widely acknowledged and the implications of caring in this context are highlighted (e.g., Teschinsky, 2000), existing research predominantly focuses on adults. Given this, less is known about the views of children of those with experience of psychosis. Literature that does currently explore the impact of living with parental mental illness (PMI) (in general) highlights both positive and challenging aspects of this. A review of qualitative research (Gladstone, Boydell, Seeman, & McKeever, 2011)

indicates that in some cases, family relationships are perceived to be strengthened; however, children also describe difficulties relating to their parent and reported negative consequences of their reduced emotional and sometimes physical availability (Riebschleger, 2004). A greater incidence of mental illness among children living with PMI is apparent (Beardslee et al., 1996; Handley, Farrell, Josephs, Hanke, & Hazelton, 2001) and caring responsibilities are frequently reported (e.g., Caton, Cournos, Felix, & Wyatt, 1998; Mayberry, Ling, Szakacs, & Reupert, 2005). Children also often describe confusion and a lack of understanding regarding their parent's illness (Gladstone et al., 2011). Although this literature offers an insight into the factors that may affect children and young people living with PMI, little is known about the potential unique influences of parental psychosis. Qualitative literature has also been criticised for predominantly providing retrospective accounts from adults (Gladstone et al., 2011). This remains problematic for several reasons. Firstly, retrospective accounts have the potential to miss important aspects of the lived experience of children and young people. Secondly, these may not accurately reflect the current care context and community treatment of mental illness, thus accounts from adults risk being out-dated. Furthermore, where children and young people are included in research, there is a great deal of heterogeneity in terms of age. This again is problematic given the likely influence of developmental factors on children's experiences.

Adolescent Development and Parental Psychosis

As children move into adolescence, the establishment of autonomy, individuation and self-identity are key developmental tasks (Allen et al., 2003; Allen & Manning, 2007). Young people begin to seek opportunities outside of the family

unit in order to achieve this. Relationships with peers and engagement with social opportunities therefore become particularly important (Allen & Manning, 2007). While supports and opportunities outside of the family play a vital role, it is theorised that the process of individuation is supported by parental connectedness and attunement (Allen et al., 2003; Cooper, Grotevant, & Condon, 1983; Moretti & Peled, 2004). This is achieved by parents and young people working together to refine their relationship; enabling young people to remain connected to their parents and family without the process of individuation and opportunities for this being compromised (Cooper et al., 1983). A qualitative study seeking to explain how children and young people manage PMI indicated that factors such as hospitalisation, exacerbations of mental illness and a lack of understanding of symptoms impaired parental connectedness. Additionally, children's ability to maintain their own identity was hindered when they were discouraged from talking about their parent's illness due to stigma and when they lacked resources to spend time away from home (Mordoch & Hall, 2008). Although this study was not specific to parental psychosis and included a wide age range of children from 6-16 years, its findings may begin to shed light on the potential challenges parental psychosis could bring to adolescent development and individuation. Given the increased risk of hospitalisation, the likelihood of symptom exacerbations (Byrne, 2007), and possible confusion associated with psychotic symptoms (Somers, 2007), young people with a parent with experience of psychosis may face additional challenges in remaining connected to their parent. Furthermore, the additional and unique social stigma attached to psychosis (Birchwood et al., 2007) and the correlation of low socioeconomic status with illnesses such as schizophrenia (Byrne, Agerbo, Eaton, & Mortensen, 2004)

may lead to young people refraining from discussing their parent's illness and lacking resources to spend time away from home, thus adding to potential challenges to the preservation of self-identity.

Having a parent with experience of schizophrenia is also associated with increased isolation and young people feeling scared by psychotic symptoms (Somers et al., 2007; Valiakalayil, Paulson, & Tibbo, 2004). Young people with a parent with a diagnosis of schizophrenia are also considered to be more vulnerable to developing psychosis and other mental health difficulties (Rasic, Hajek, Alda, & Uher, 2014). A review of the literature by Laurens et al. (2015) highlights the role of genetic and environmental factors in the development of psychosis. Although there are common markers in the developmental trajectory including familial and genetic predispositions, obstetric complications, cognitive and behavioural difficulties, childhood trauma and attachment difficulties (Baron, Gruen, Asnis, & Kane, 1982; Bentall & Fernyhough, 2008; Maier et al., 1993; Marenco & Weinberger, 2000; Mortensen, Pedersen, Melbye, Mors, & Ewald, 2003; Varese, Smeets, & Drukker, 2012), the extent to which this trajectory is influenced by biological, environmental and/or relational factors is less well understood. The influence of family context and the role of multifinality in developmental psychopathology is also considered, for example, there will inevitably be variation in how similar early experiences affect people (if at all) (Cicchetti & Rogosch, 1996; Morris, Silk, Steinberg, Myers, & Robinson, 2007). Literature exploring the development of borderline personality disorder (BPD), suggests that children with a parent with experience of BPD may become vulnerable to developing features of the disorder through the interaction of genetic factors and insecure/disorganised attachment relationships with their parent

(Fonagy & Luyten, 2009; Gunderson & Lyons-Ruth, 2008). While Huntsman (2008) indicated that many children living with PMI develop secure attachments, they also noted that children of parents with severe mental illness are at greater risk of impaired attachments. A recent review by Engur (2017) suggested additional challenges brought about by parental psychosis that may give rise to interactional difficulties and poor attachments. The prevalence of metacognitive and affect regulation difficulties in psychosis (Moritz, Ferahli, & Naber, 2004; van der Meer, Wout, & Aleman, 2009) may also affect a parent's ability to recognise and respond to a child's emotional needs. Coupled with literature regarding potential genetic vulnerabilities to the development of psychosis (Baron et al., 1982; Maier et al., 1993; Murray et al., 2004) and considering the role of early intervention in improving outcomes for psychosis (Bird et al., 2010), the importance of recognising and understanding the needs of this population is clear. Despite this, there are a number of protective factors which may mitigate the impact of insecure attachments including child temperament, relationships with others and experiences later in life (Huntsman, 2008; Pearson, Cohn, Cowan, & Cowan, 1994).

Impact of Caring

Family members often act as primary supports or carers to those with experience of psychosis (Kuipers, Onwumere, & Bennington, 2010). While there is an abundance of literature regarding the impact of caring for someone with experience of psychosis, this is predominantly adult focused. In view of the developmental tasks faced by adolescents, their experiences and needs are likely to differ. While young carer research may shed some light on this, as already discussed, the possible unique influences of parental psychosis are not explored. The shift to

recognising recovery from psychosis as living a meaningful life in the presence or absence of symptoms (Brown & Kandirikirira, 2007; Morrison et al., 2016) has led to an emphasis on community treatment. Alongside the implementation of health and social care integration in the UK, this potentially increases the likelihood of young people living with and/or caring for their parent. Although this is a positive alternative to parent-child separation due to hospitalisation, this may lead to an increased requirement for family support. There are factors specific to psychosis that may play a role in inflating young people's perception of responsibility and care for their parent. These include increased risk of self-harm and suicidal ideation in psychosis (Hawton, Sutton, Haw, Sinclair, & Deeks, 2005; Hawton, Sutton, Haw, Sinclair, & Harriss, 2005), reduced cognitive and social functioning (Dickerson, Sommerville, Origoni, Ringel, & Parente, 2001; Wykes, Huddy, Cellard, McGurk, & Czobor, 2011), and a greater risk of relapse and hospitalisation (Byrne, 2007; Miller, 2011). Existing literature indicates that young carers often perceive a role reversal with regard to parent-child relationships (Gladstone et al., 2011); a concept commonly known as *parentification* (see Hooper, 2007 for discussion of definition). While it is acknowledged that a degree of responsibility of this nature can be beneficial, early parentification can pose further challenges to adolescent development, with young people sacrificing their own needs in order to meet those of their parent (Hooper, 2007). Despite this, having a caring role may bring about opportunities for young people to develop a sense of autonomy and responsibility which may facilitate individuation. Young people also often report a sense of self-worth and enjoy being able to make a positive impact (Handley et al., 2001; Mayberry et al., 2005).

Interventions and Supports

While various educational programmes and interventions have been developed to support children and young people affected by PMI (Reupert et al., 2012), these are not routinely implemented in the UK and the views of young people on the usefulness of such programmes have rarely been sought. Family interventions are acknowledged to be effective in improving outcomes for those with experience of psychosis (NICE, 2014a, 2014b; Scottish Intercollegiate Guidelines Network [SIGN], 2013) and are also suggestive of positive outcomes for family members (Lobban et al., 2013). Despite this, family interventions are not routinely offered and a recent review by Bucci, Berry, Barrowclough, and Haddock (2016) outlined a number of barriers to implementation on an organisational, clinician and service user/family level. Furthermore, although the inclusion of offspring is recommended (SIGN, 2013), there is a lack of literature exploring the impact on and inclusion of children and young people.

Current Study

Although existing literature sheds light on the impact of PMI (in general) on children, less is known about the potential unique effect of parental psychosis and how this might impact on adolescent development. It is possible that there are aspects of having a parent with psychosis that may give rise to additional challenges and opportunities for maturation. This may be further complicated by the more recent emphasis on community treatment; with young people more often living with and potentially caring for their parents. Alongside the genetic and environmental vulnerabilities associated with psychosis, the need to identify and recognise families affected by psychosis is evident. The current study therefore aims to establish how

young people with a parent with psychosis conceptualise themselves in the context of their parent's care and involvement with services. Understanding their experiences will hopefully shed light on how young people negotiate this in the context of maturation. This hopes to inform services across health and social care and other agencies regarding how young people may best be supported. Considering that existing literature frequently reports retrospective accounts from adults (Gladstone et al., 2011) and the importance of consulting young people in the development of services and guidelines (Redsell & Hastings, 2010) views will be sought from young people directly.

Method

Design

In light of the explorative nature of the research and the aim of explaining how young people conceptualise themselves in the context of their parents care, a qualitative methodology was adopted and a grounded theory approach was employed. Grounded theory is considered useful in providing new understandings of phenomena that are rooted in those experiencing the phenomena in question. It aims to develop an inductive theory to conceptualise people's views and experiences; informing services and interventions (Charmaz, 2014). A constructivist approach to grounded theory refutes the concept of uni-dimensional, external reality, allowing for integration of subjective experience with social conditions. Research by Mordoch and Hall (2008) highlighted the influence of life experiences and social circles on children's expectations of family life. It is likely that social and family factors will impact on young people's perception of their roles in relation to their parent's care and support services. A constructivist approach to grounded theory is therefore

considered to lend itself well to exploration of the current research question and is congruent with the researcher's philosophical stance; recognising the influence of interactive processes between the researcher, participants and the data and acknowledging the role of prior knowledge and preconceptions (see Memo 1, Appendix F).

Participants

Eligibility. Young people were eligible to take part if they were aged 12-18 years (inclusive), identified themselves as having at least one parent with experience of psychosis (including schizophrenia-type disorders and/or bipolar disorder), and perceived themselves as having regular contact with this parent. Whether or not young people identified themselves as a young carer was not considered important for the purpose of this study. Although differences in presentation and symptoms of schizophrenia-type disorders and bipolar disorder are acknowledged, as outlined, these diagnoses are associated with a certain degree of complexity and commonalities in terms of presentation and treatment experiences, thus young people with a parent with either presentation were included.

Young people were excluded if their comprehension of the English language prevented them from understanding the consent process and participating in the interview without the need of a translator. Young people with a known learning disability were also excluded. Acknowledging the varied needs and particular challenges faced by these populations, their inclusion would add to the heterogeneity of the sample; making generation of specific theory problematic. While the value of exploring these issues is acknowledged, this is beyond the scope of this study.

Sample size. Sample size in grounded theory is generally guided by theoretical saturation; the point at which no further properties of a category are established (Charmaz, 2014). This is impacted by a number of factors including heterogeneity of participants, variation of experience, the richness of data gathered, and the skill of the interviewer (Charmaz, 2014; Mason, 2010). In view of this, sample size cannot be predetermined. It is also acknowledged that theoretical saturation can be difficult to declare with certainty. The sample size for this study was therefore guided by theoretical sufficiency (Dey, 1999). This concept offers a more pragmatic approach to determining sample size, proposing that categories are suggested by data as opposed to being saturated by data.

Characteristics. 11 young people participated in the study. Participants were aged between 14 and 18 years (mean = 15.6 years); eight were female and three were male. Two participants reported their parent to have experience of a schizophrenia-type disorder, seven reported their parent to have experience of bipolar disorder with psychotic symptoms, one reported bipolar disorder with no known symptoms of psychosis and one reported their parent to experience psychotic symptoms with a queried diagnosis of bipolar disorder. Two participants reported their father to be the affected parent and the remaining participants reported this to be their mother.

Procedure

Service user and family involvement. Relevant parents and young people were consulted in order to seek feedback on methods of recruitment and their perceived acceptability, parent and participant information and consent forms, consent processes, the interview schedule and, the use of language and terminology. Research materials were also presented to the Scottish Children's Research Network

(ScotCRN) Young Person's Group. The design and materials were amended in consideration of feedback.

Recruitment. Participants were initially recruited via third sector organisations and subsequently, through NHS services due to recruitment difficulties. Participants were sought from organisations and services supporting both young people and adults in Scotland. This aimed to broaden recruitment opportunities, allowing for potential participants to be identified via services supporting them or their parent. 14 third sector organisations and nine NHS services (across three health boards) were involved in advertising and recruiting for the study. These included young carer organisations, youth hubs, organisations supporting adults with mental illness (and their carers), child and adolescent mental health services (CAMHS), adult psychology services, and community mental health teams. The research was advertised within services through flyers and posters via their websites and social media pages (where relevant). A research website (Appendix G) was also developed and the researcher delivered information sessions to staff and relevant groups attended by potential participants. Staff were provided with details of the study and asked to disseminate recruitment packs (Appendix H) to young people who were eligible to take part. Those responding to adverts were prompted to contact the researcher directly. Contact options included email, phone, text and through the research website. Those who expressed an interest provided their preferred method of contact and a suitable time was arranged to speak with the young person either face to face or via the telephone in order to ensure their eligibility. Providing they met inclusion criteria, a suitable time and place was arranged in order to carry out a

one to one interview. Interviews were conducted at least 24 hours after being provided with information about the study.

It is worth noting here that the study faced significant recruitment issues. Gladstone et al. (2011) reported similar issues in other qualitative studies with children with experience of PMI. It is possible that these difficulties were exacerbated in this study due to the nature of the population being accessed. Difficulties engaging people with experience of psychosis in research and clinical settings are noted (Dixon, Holoshitz, & Nossel, 2016; Jørgensen et al., 2014), thus adding to challenges accessing their children. Furthermore, through consultation with recruiting staff, issues such as social stigma and staff finding it difficult to speak with young people about their parent's illness were perceived barriers. Implications of this are further outlined within the discussion and documented within Memo 2 (Appendix F).

Ethical considerations. In line with the British Psychological Society (2011), the study aimed to ensure that risk of harm to participants was no greater than that encountered in their everyday lives. The study was reviewed and given a favourable opinion by the *University of Edinburgh, Department of Clinical and Health Psychology Ethics Research Panel* and the *South East Scotland Research Ethics Committee* for recruitment through third sector and NHS services, respectively (Appendix I).

Risk of distress to participants. Consent was sought with participants' full knowledge of the research. Participants were encouraged to advise the researcher if there were topics that they did not wish to discuss prior to the interview and advised that there was no obligation to discuss anything they did not wish to. The researcher

remained sensitive to signs of distress and the option to terminate or break from the interview was provided. All participants were debriefed following the interview and their personal supports and contact details for generic supports were outlined in a post interview information form (Appendix J). The research website also contained web links to potentially useful organisations/support services.

Risk of disclosure of parental mental illness to young people. The method of recruitment aimed to avoid disclosure of parent's illness in cases where this was not realised by the young person. For participants recruited via services supporting their parent, parents would be unlikely to provide information about the study if their child was unaware of their illness. For participants recruited through services supporting young people, staff were asked to only disseminate information packs to those who were aware of their parent's illness.

Consent. All participants were encouraged and advised to involve a trusted adult in their decision to take part in the study. This aimed to provide young people with practical and emotional support in their participation (where necessary) and promote transparency of the research. While it is acknowledged that it is good practice to obtain parental consent where a young person is under the age of 16 (BPS, 2011), in view of the sensitive nature of the research and considering relevant guidelines and legislation (ScotCRN, 2012; the *Age of Legal Capacity (Scotland) Act 1991*), it was felt appropriate to gain consent from participants only. This also ensured that in cases where parents were unavailable, may have wished to obstruct participation for reasons against the best interests of the young person, or were considered not to have the capacity to consent, young people were not disenfranchised and could still take part if they wished. Of note, all participants

involved a trusted adult in their decision to take part and in most cases, this was their affected parent.

Data collection and analysis. In accordance with grounded theory, data was collected and analysed simultaneously (Glaser & Strauss, 1967). Sampling was initially purposive with theoretical sampling then being guided by data analysis.

Data collection. Individual interviews were conducted with participants. Informed consent (Appendix K) was sought prior to interviews. Initial interviews remained relatively open ended, being predominantly guided by participants. Lines of enquiry then became gradually more specific; being guided by data analysis and the emergence of categories (Appendix L). Interviews were audio recorded using an encrypted and password protected voice recorder and interviews were 29-62 minutes in duration (mean = 44 minutes). A brief written task was also completed within the interview as a means of gathering information about perceived parental supports (Appendix L). Following interviews, participants were debriefed and completed a post interview form. The interview process and schedule was piloted by the first two participants opting in. Their feedback was sought with the intention of altering these if necessary. This process also allowed for the identification of potential practical, recruitment and methodological issues. In line with theoretical sampling, where it was felt that further information from participants would assist in theory development, they were invited to a second interview. Consent to be contacted for this purpose was sought. Second interviews followed the above procedure. Recruitment continued until theoretical sufficiency was perceived to be achieved.

Data analysis. The final data set consisted of 12 interviews. All participants completed one interview and one completed a second interview in line with

theoretical sampling. Memos were also completed and were included as part of the analysis. Audio data was transcribed verbatim and NVivo software (Version 10; QSR International, 2012) was used to facilitate analysis. Data was managed in accordance with an established data management plan which was informed by University and NHS guidelines. Analysis was guided by Charmaz (2014). Initial coding enabled line-by-line analysis of the first five transcripts; allowing the researcher to become close to the data with the aim of identifying categories and hypotheses to explore further through new lines of enquiry. A process of focused coding was then adopted; allowing for grouping of codes into potential categories (see Appendix M for example of transcript and coding). Analysis remained open to allow for subsequent interviews and the generation of new codes and categories to influence and inform earlier data. The identification of categories then enabled theoretical coding to take place, whereby categories were interlinked and meaningful and prominent concepts were derived in order to generate theory (Charmaz, 2014).

Ensuring quality. In accordance with grounded theory and with the aim of remaining fully aware of pre-existing ideas and facilitating theoretical coding, the researcher engaged in memo writing throughout the process. This enabled an audit trail regarding decision making and aimed to increase transparency. The process of memo writing also aimed to increase theoretical sensitivity; ensuring that codes and categories closely represented data as opposed to pre-existing ideas and hypotheses. Feedback regarding interview style was sought from supervisors with the aim of promoting adherence to a grounded theory approach. A method of triangulation was also used through gaining assistance from supervisors in coding data, checking

categories and emerging theories and through comparing and contrasting emerging theory with existing literature.

Results

The substantive theory generated offers a tentative explanation of how young people establish and balance their roles in relation to parental psychosis and adolescence. It also provides an understanding of factors that potentially influence this process and successful engagement with roles. As outlined, the term *psychosis* is adopted within this paper to encompass schizophrenia-type disorders and bipolar disorder, thus, the term *parental psychosis* is used to include parents with experience of schizophrenia-type disorders and bipolar disorder. An overview of the model will be presented initially and theoretical categories and underlying processes emerging from analysis will then be discussed, using participant quotes to promote understanding on a conceptual level. For the purpose of anonymity, participant names are pseudonyms. In line with recommendations by Birks and Mills (2011), the findings are presented in isolation from existing theory and literature, using the discussion to situate the theory in context of this.

Overview of Model

Findings indicate that the way in which young people conceptualise themselves in the context of parental psychosis and their parent's care is a complex process, influenced by a number of factors. Although young people generally seem to identify with a role of responsibility and care for their parent, this appears dependent on perceived parental needs and support; thus, their role remains open to change with fluctuation of illness and familial supports. At the core of the model is how young people negotiate their role in relation to their parent's care in the context

of adolescence; balancing caring for and/or living with a parent with experience of psychosis with “being a teenager”. Again, young people seem to move between these roles depending on their perception of their parent’s needs and supports. Their success in fulfilling and balancing these roles appears to be facilitated and challenged by a number of direct and indirect influences. Direct influences include: having appropriate information (regarding presentation, management and availability of supports, that is specific and formulation based), talking to others, and receiving support. Young people perceiving adults to view them as “too young”, feeling scared and confused, and social stigma relating to parental psychosis are also influential. Young people voice mixed feelings regarding their role in relation to parental psychosis, describing wanting to help, “getting used to it”, and noticing the impact on their lives.

Figure 2.1 depicts a schematic representation of the substantive theory.

Where positive and negative symbols are used, these arrows seek to explain the (general) positive or negative impact of factors on young people’s roles in caring for and/or living with parental psychosis and being a teenager. The direction of these arrows is therefore not necessarily indicative of the reciprocity of relationships. Solid arrows represent direct influences on young people’s roles in living with and/or caring for a parent with psychosis and being a teenager. Dashed arrows indicate indirect influences on these roles.

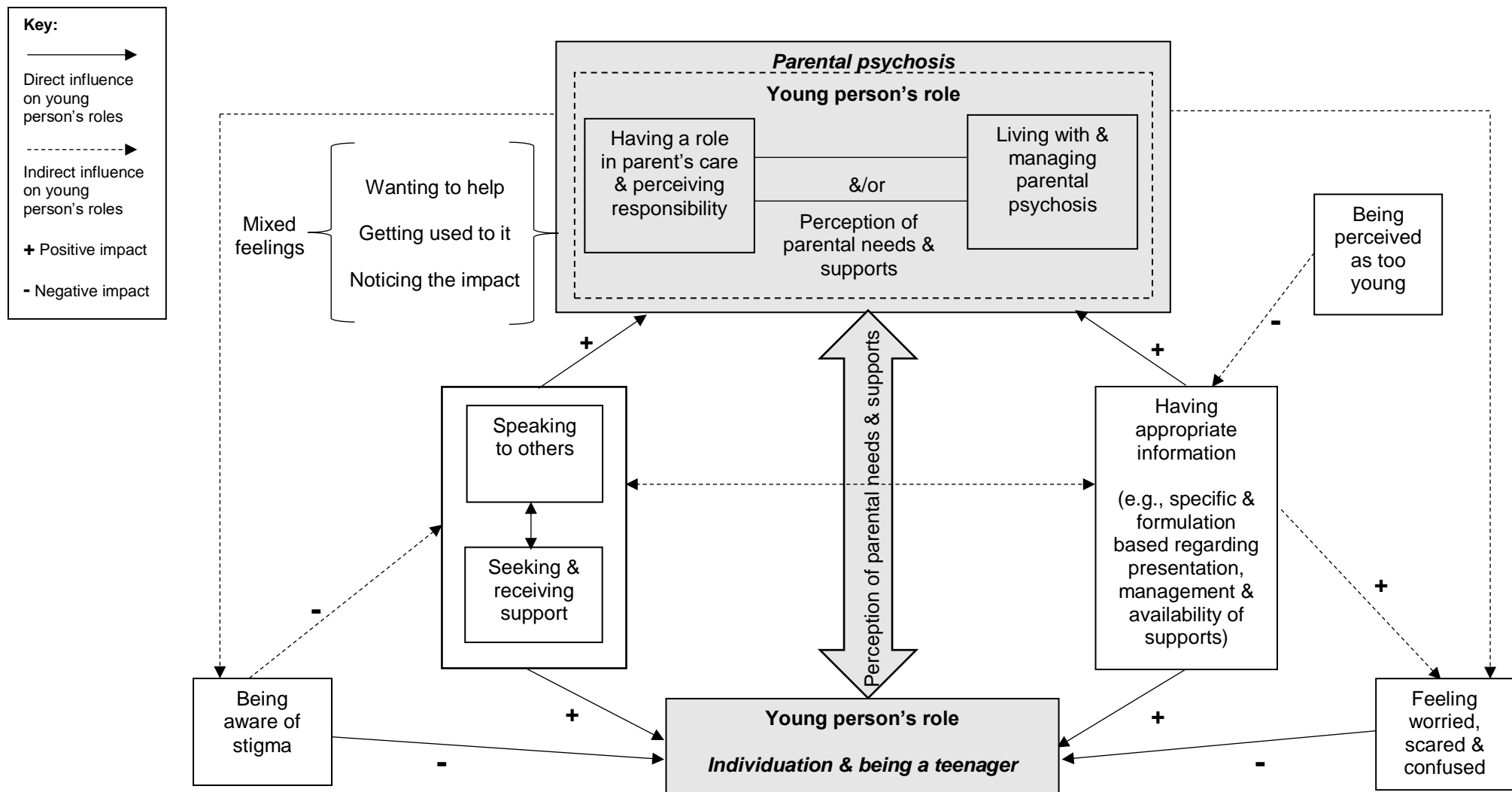


Figure 2.1. A substantive theory of how young people establish and balance their roles in relation to parental psychosis and adolescence and factors that potentially influence this process and successful engagement with roles.

Establishing a Role

Having a role in parent's care and perceiving responsibility. Most young people perceived themselves to have a role in caring for and supporting their parent and this tended to fluctuate depending on their perception of parental needs and supports. Participants were presented with a diagram comprising concentric circles (with their parent in the centre). They were asked to indicate supports available for their parent and the proximity of these to their parent. Although not all young people identified themselves as carers, the vast majority positioned themselves towards the centre of the diagram, closest to their parent (Appendix N). Participants often reported a sense of responsibility for their parent's care and wellbeing and described role reversals, for example, fulfilling a parental role. *"Aye, so it's like, like I'm the Mum – I'm like shouting at her about mess like she should be shouting about mess."* (Hannah). Young people frequently reported providing emotional and practical support to their parent. Practical support included carrying out household tasks, caring for siblings and ensuring that their parent was adhering to prescribed medication. Emotional support included managing distress, offering reassurance (often in relation to psychotic symptoms) and having a role in motivating their parent.

I thought to myself if I, even as a daughter, could make my Mum feel a little bit more erm, I don't know how to explain it, a little bit more comfortable then maybe she wouldn't feel so jumpy around other people. (Katie)

Frequently, young people spoke of offering support at times of crisis, including managing hospital admissions and disclosures of suicidal ideation and intent. Two of the eleven participants spoke of being directly involved in treatment decisions and

interventions, for example case reviews and family interventions. Other participants reported having little or no involvement with services supporting their parent.

Despite many expressing a wish to be better informed and involved with discussions with regard to their parent's mental health, many reported being dismissed as too young by health and social care staff involve in their parent's care.

Living with and managing parental psychosis. As well as (often) perceiving a role in caring for their parents, young people also spoke of more general implications of having a parent with experience of psychosis that did not necessarily require them to adopt a caring role but that impacted on the way in which they communicated with and related to their parent. They often reported an element of unpredictability with regard to their parent's presentation and described rapid changes in mood and other symptoms such as psychosis. This led them to adopt a role in monitoring triggers; adapting their behaviour and communication with the aim of appeasing parents, managing fluctuations and preventing further exacerbations. *"Another fear I would say is constantly like worrying about her and constantly thinking, well when you're in the house, constantly worried to say the wrong thing in case it sets her off."* (Katie). Young people often described an awareness of the impact of PMI on their parent's ability to fulfil a parental role.

Like when she was like not well and stuff and she was just kind of like on bad days like you could just like go in and cook yourself dinner and stuff.

Obviously like go in and run yourself baths and try and like do your homework by yourself and it's obviously stuff that you're gonna need to do at some point but you just need help from your Mum. (Eleanor)

The impact on their parent's emotional availability was also noted, influencing young people's willingness to seek comfort from their parent. Young people often opted not to share experiences of stress for fear of making things worse for their parent; making efforts to conceal their distress in front of them. *"Coz I ken (know) that I need to like make myself alright for her coz if I'm not alright then it worries her more."* (Hannah). Young people also described sometimes being directly influenced by psychotic symptoms, for example parents being paranoid about the safety of their children or voicing aggressive or violent intentions.

Like, I don't go out much...my Mum doesn't like me being out late because she thinks something's going to happen to me like. The voices tell her like 'something's happened to her' so she kind of believes it and she panics.
(Beth)

Eight of the eleven young people recalled experiences of their parent being admitted to hospital. Many played a role in the admission, for example, calling for help. Most young people reported having little involvement with staff while their parent was hospitalised and many described visiting their parent in hospital to be a frightening experience.

Individuation and being a teenager. Young people's perception of their role with regard to caring for and/or living with their parent was further complicated by their developmental stage. Participants were very aware of the impact of this on their opportunities for individuation. This included opportunities for connecting with friends, school and maintaining an identity. Friendships were difficult to develop due to reduced opportunities to go out; with young people worrying about their parent; opting to stay in with the aim of ensuring their safety and wellbeing. Young people

also described finding it difficult to invite friends over, feeling concerned about how their parent may present.

It was a lot to kind of explain to my friends 'well we can't go to my house for dinner, do you think we could go to yours again?' kind of things after school.

It was difficult to make friends because of that like. (Katie)

Participants also reported school demands to be more difficult to manage in the context of stressors at home. Some young people spoke about school being a good distraction; somewhere that enabled them to get away from the stress at home and connect with their own interests and identity. Many described a sense of losing a childhood and growing up faster. This was often associated with feelings of sadness, *"It makes me not really be able to go out as much. I can't do as much things as I'd like to. It makes me feel like I am not getting the great childhood that everyone should."* (Lisa); however, some young people did acknowledge the opportunities this provided them with in order to develop new skills. *"I can only thank my Mum really because she taught me how to do like washing and how to tidy and all that and how to clean. So it's kind of like life skills."* (Beth)

Having mixed feelings. Establishing a role in the context of living with and/or caring for their parent often resulted in mixed feelings for young people. The majority demonstrated a great deal of care towards their parent, often indicating that they wanted to help and make a difference to their wellbeing. Often, these feelings appeared to be in conflict with young people noticing the impact of living with and/or caring for their parent, with participants describing "getting used to it" and perceiving no alternative other than to "get on with it". For some participants, this caused feelings of resentment which frequently led to feelings of guilt; with young

people then minimising the impact of their parent's illness on themselves, in some cases idealising their parent.

I've got mixed feelings, like sometimes I feel really really bitter and I feel like, I feel like my Mum's illness has taken my childhood away...and, other times it doesn't really bother me because it's what I've always lived with....sometimes I feel like I start to blame my Mum like I don't think it's her fault and I shouldn't be blaming her but sometimes it's just what my mind jumps to. (Sara)

Balancing Roles

Young people described a tension in balancing their perceived roles and responsibilities related to caring for and/or living with their parent with being a teenager.

Interviewer: OK, so what kind of responsibilities did you feel you had at the time?

Participant: Well, obviously the basic things that teenagers have like school and things erm, another thing I would think was my Mum erm, like helping her, making dinner, doing washing, doing as much as possible. (Katie)

Their connection with these roles appeared related to young people's perception of their parent's needs and supports. *"Well even if I wasn't there she at least had some kind of help. Now there's nothing (having been discharged from health service)."*
(Sara)

I feel like I'm more of a teenager now, like I feel like I can get on with my teenage life, like I can go out with friends and I don't know, go to parties and whatever. I feel like I can be more like that now because I'm not always

*worrying about my Mum because I know she's in a better place now
(regarding mental health). (Eleanor)*

Having information. Making sense of psychosis. Many young people struggled to make sense of their parent's experience of psychosis. They described particular difficulty understanding psychotic symptoms and reported seeing a difference in their parent during these times, often leading them to feeling disconnected, worried, scared and confused. This also seemed to have an impact on their ability to connect with life as a teenager. *"I can see about the anger and that his mood changed really fast but I don't know anything about how and why he (describes content of delusional beliefs) ...It's all just really confusing."* (Ben). Ben later described the impact of feeling worried and confused about psychotic symptoms when spending time away from home: *"I guess it just made me feel really bad at that time and I, coz I was restricted in doing stuff quite a bit because I had to worry about him while I was out."* (Ben). Having opportunities to understand and make sense of psychosis was considered normalising and reassuring. *"(it's) kinda like reassuring that there is treatment and other people do go through it."* (Nicola).

Having appropriate information. Young people described wanting more information, although they reported the quality and relevance of information to be an important factor. Some young people described generic information to be helpful in normalising their parent's difficulties but most spoke of wanting information specific to their parent's situation in order to help them understand potential triggers and maintaining factors.

*I feel like leaflets and things don't necessarily tell you what these erm
illnesses actually, you know, how to respond to the illnesses for a start or*

what they actually erm mean in a person. So, you'd really have to sit down with somebody and really talk to them about it before you're going to be able to understand it...it's (talking to others) opened my eyes to what bipolar is and how as a person even though I can't go out and cure it myself I can contribute to my Mum feeling better by doing different things. (Katie)

Young people valued discussions with their parents and their parent's healthcare team in order to get a fuller understanding of their parent's presentation.

He (psychiatrist) also had a meeting with me, my Auntie and my cousin and kinda explained why she was acting why she was and he kinda went through it like it was just helpful...that totally helped like make sense of it.(Hannah)

Despite this, most young people reported not having any involvement with their parent's support team and reported a wish to be better informed by them, particularly during times of hospitalisation. Many were unaware of the role of staff within health services.

Young people described wanting information to help them respond in times of crisis. *"So I phoned NHS 24/7 (NHS 24) and I spoke to a few people...so like I felt quite like good dealing with it and if it happens I know what to do."* (Nicola).

Although most participants described wanting more information, some reported receiving too much information about specific elements of parental psychosis. *"Most of the thoughts (relating to parent's psychosis) that I did get told, I wish I never knew."* (Hannah). There was also a tendency for some young people to assume responsibility alongside having information; seeking information with the aim of being able to reduce symptoms or help their parent "recover". *"I wanted to know as much about it so I could help in any way I could."* (Lisa). Therefore, the content and

way in which information was delivered seemed to be an important factor in relation to how young people engaged with and balanced their roles in relation to their parent's care and being a teenager.

Being perceived as too young. Young people valued having information from their parents, other family members and staff involved in their parent's care. They reported a significant barrier to receiving this information was being perceived as too young by adults, reporting a reluctance from adults to share information and involve young people in discussions regarding their parent's care and experience of psychosis. Participants reported a belief that adults were concerned about causing them upset and/or perceived them as too young to understand. Given that young people often perceived themselves as having a major role in their parent's care, this frequently resulted in them feeling de-valued, undermined and shut out by services.

They were like 'ah, she's a wee (little) wain (child), she won't understand' but they did nae (not) speak to me to know if I would understand or not ...as I got older I was like 'er, I'm like one of the main people involved in this like I'm worried about her' and obviously because my sister was a few years older than me, she would get to know stuff and she wasn't allowed to tell me and that because they said that it would like, I don't know, upset me or something but the whole things upset me...maybe we wouldn't have understood but maybe if you actually sat down with us and put it in a simpler form. (Eleanor)

Speaking to others. Young people valued talking to others and described receiving emotional support through this. Despite this, participants described a tension between wanting to speak to others about their parent's illness and worrying

about the impact of this. They reported concerns with regard to stigma and described feeling worried about adults over-reacting to information; with many having experience of this. This resulted in young people remaining cautious about who they chose to speak with.

Like I try to keep my teachers for the very very very last people just because in case like they misinterpret it and they think 'OK, what is happening in that household?' In case it becomes an actual like police matter because like in the past that's actually happened on one occasion but after I explained it to the teacher she actually went 'oh, I thought you meant something else'.

(Luke)

Close friends were frequently cited as good supports but young people were reluctant to speak with wider peer networks. Participants opted to speak with friends who were affected by mental illness as they felt that they would be more likely to understand their situation. *"Erm, well I do talk to my closest friend about it but like coz like her Gran has schizophrenia so she kind of knows what it's all about."* (Sara). Speaking to others allowed young people to feel more connected to others, thus promoting individuation and facilitating access to supports and information.

Seeking and receiving support. As discussed, young people reported speaking to others as one of the main supports in getting their emotional needs met. Although not all young people identified themselves as carers, many valued young carer organisations in offering support and signposting. Many participants reported positive experiences of attending young carer groups. *"I go to Young Carers...you can just go there and be yourself and you won't get bullied...you can just be who you are."* (Becky). Participants spoke of young carer workers and CAMHS staff

advocating for them, for example liaising with schools and parents, explaining PMI and offering advice and promoting young people to connect with their own values.

She's (young carer worker) just done loads of things like from emailing like college and after high school just before I went to college I applied for carers allowance...she helped me with the application form for that like filling it out because I had no idea what to write on it...she's spoke to (name of cousin) and my Auntie on the phone quite a few times as well...She would just keep everybody in the loop with what was happening with me and stuff like that.
(Hannah)

Participants also valued opportunities to spend time away from home. Family played a vital role in supporting young people and their parents. They were often the first source of support for young people, offering emotional support, sharing perceived responsibilities of care for their parent and providing accommodation when parents were unable to look after them. Thus, familial supports played a vital role in helping young people to balance roles in relation to care, responsibility and being a teenager.

Discussion

The model promotes an understanding of how young people conceptualise themselves in relation to their parent's care and adolescence by offering a tentative explanation of how they establish and balance their roles in relation to parental psychosis and adolescent development—a process that appears very much dependent on young people's perception of parental needs and supports. It is well situated in the context of social constructivism, allowing for the diversity of experience and family context to be understood within one theoretical framework. This is demonstrated

through the central role of young people's perception of parental needs and supports in establishing and balancing their roles in relation to parental psychosis and adolescent development. Therefore, the potential for movement and variability across time and family context is emphasised. The model is indicative of a number of factors that either facilitate or challenge young people's balance and negotiation of roles, including having appropriate information regarding presentation and management of parental psychosis (that is specific and formulation based) and an increased awareness of available supports. In their review, Gladstone et al. (2011) highlight the lack of representation of children and young people in existing literature and discuss the implications of adult views (as participants and researchers) and assumptions about childhood in preventing a deeper understanding of young people's experiences. Although central to grounded theory, it is worth noting that the model is rooted in young people's experiences. Young people are positioned as experts in their experience and their personhood and agency is acknowledged, therefore recognising and respecting perceptions of their realities. Through the use of memo writing, the researcher's assumptions and preconceptions are recognised with the intention of remaining responsive and sensitive to young people's accounts. Unlike much of the existing literature, the model generated is therefore grounded in the realities of young people and offers a further understanding of issues that are pertinent to them.

In line with Gladstone et al.'s (2011) review, the effect of PMI on peer relationships (such as reduced social opportunities), parental relationships and caring responsibilities is highlighted. Influences of social stigma, an absence of information regarding PMI, young people having mixed feelings towards their parent and a lack

of involvement with services are also echoed here. While the model supports what is already known about factors regarding the impact of PMI, it expands on existing knowledge by offering a tentative explanation of how these factors may relate to young people's success in balancing roles in relation to their parent's care with adolescent development. Findings reiterate the importance of support and information for young people in this process but extend our understanding of information sharing through offering an explanation of the type and quality of information young people require to support them in managing parental psychosis in the context of adolescence. Furthermore, findings shed light on the unique impact of parental psychosis, specifically: difficulties in young people managing and making sense of psychosis, dealing with crises such as disclosures of self-harm and suicidal intent, being directly influenced by psychotic symptoms such as delusional beliefs, and feeling disconnected from parents during periods of psychosis. Although influences of managing and monitoring unpredictable and rapid mood changes and coping with hospital admissions have been reported elsewhere (Mordoch & Hall, 2008), the current findings indicate that these factors have particular relevance to this population. In addition to being well supported by existing research, the model is well situated within the context of existing theoretical frameworks such as developmental, attachment and family systems theories (Ainsworth, 1979; Allen & Manning, 2007; Bowen, 1978; Bowlby, 1969). Theoretical concepts including parentification, parental idealisation (Blos, 1962; Steinberg & Silverberg, 1986) and models of recovery (McGlashan, Levy, & Carpenter, 1975) are also of relevance and are discussed in the context of current findings.

Drawing on theories of adolescent development, as indicated by Allen and Manning (2007), the establishment of autonomy and self-identity is key to individuation. At the core of the model is young people's balance and negotiation of their roles in relation to parental psychosis and adolescent development. The findings highlight a number of challenges and opportunities faced by young people with a parent with experience of psychosis in engaging with activities that may facilitate individuation. These include challenges in maintaining friendships and school commitments and opportunities for the development of autonomy and responsibility through a caring role. Similarly to Mordoch and Hall (2008), in this study, young people also reported difficulties in remaining connected with their parent, particularly during exacerbations of illness and psychosis. A lack of parental connectedness has implications for young people's ability to achieve individuation (Allen et al., 2003; Cooper et al., 1983; Moretti & Peled, 2004), thus potentially adding further challenges to individuation and adolescent development.

In line with previous research (e.g., Handley et al., 2001; Mayberry et al., 2005) findings indicate that in many cases, young people perceive responsibility for their parent's care and wellbeing and describe fulfilling a parental role. As described by Hooper (2007), this may lead to young people sacrificing their own needs in order to meet those of their parent. This concept is captured within the current model through the tension between young people's role in their parent's care and meeting their own developmental needs. Despite this, the findings indicate that young people also express a sense of pride in the role; enjoying being able to make a positive impact on their parent's wellbeing and appreciating the opportunity for developing new skills; potentially providing opportunities for maturation. As outlined by Hooper

(2007), attachment and family systems theories offer a framework in which to conceptualise the process of parentification and the established grounded theory is supported by and well situated within this context; highlighting the impact of parent-child interactions and familial influences on how young people perceive themselves in the context of their parent's care. The current findings indicate that young people often note the impact of psychosis on their parent's emotional and physical availability which appears to affect parent-child interactions, sometimes leading to a sense of disconnection. This also impacts on young people's perception of their parent's ability to fulfil parental tasks, leading them to engage with parental roles and increasing the likelihood of parentification. While family systems theory acknowledges the role of parent-child interactions, the wider family network is considered to play a mediating role in how parentification is perceived and/or played out. This sheds light on the central role of the perception of parental and family supports in young people's engagement with caring roles and life as a teenager.

Similarly to Mordoch and Hall (2008), findings indicate that young people demonstrate mixed feelings towards living with and/or caring for their parent. Findings suggest that young people care very much for their parent; often enjoying having a caring role and having a positive impact. These feelings can be in conflict with young people noticing the impact of parental psychosis and perceiving an obligation to care for them. For some, this leads to feelings of resentment (which is often associated with expressions of guilt). In the current study, young people sometimes made efforts to minimise the impact of their parent's illness; idealising their parent and absolving them of responsibility. It is theorised that *de-idealisation* of parents is a developmental task that promotes freedom to differentiate from

parents; playing an important role in establishing autonomy (Blos, 1962; Steinberg & Silverberg, 1986). Furthermore, Harrop and Trower (2001) posit that alongside disruption in other processes of maturation, failure to de-idealise parents may contribute to the development of psychosis. Their theory suggests that the development of psychosis within late adolescence can be explained by the phenomena of *blocked adolescence* (a failure to accomplish psychological processes of maturation), which prevents resolution of stress and conflict that typically emerges within this period. Alongside what is known about the familial predisposition to and intergenerational nature of psychosis (Baron et al., 1982; Maier et al., 1993; Marengo & Weinberger, 2000; Mortensen et al., 2003), the current model perhaps very tentatively adds support to Harrop and Trower's theory and the development of psychosis through its emphasis on the potential impact of parental psychosis on adolescent development. Although further research would be required to explore this concept, it is possible that (in view of the potential impact of parental psychosis on maturation and in the context of Harrop and Trower's theory of blocked adolescence) the increased vulnerability of young people with a parent with experience of psychosis developing psychosis themselves may be influenced by an increased possibility of blocked adolescence. This therefore potentially adds to our understanding of possible contributory factors to the increased vulnerability of this population developing psychosis and other mental health difficulties (e.g., Hans, Auerbach, Styr, & Marcus, 2004; Maier et al., 1993). The model also outlines potential facilitators and barriers to young people successfully engaging with and balancing roles in relation to their parent and individuation and being a teenager.

This therefore adds to our understanding of factors that may support adolescent development and mitigate the potential impact of parental psychosis on this process.

Recovery models shed light on the potential impact of young people minimising parental psychosis and having a lack of information and opportunity to explore this. McGlashan et al. (1975) theorised that people with experience of psychosis are more successful in integrating with society when they are able to take an explorative and accepting stance towards their experiences. Sealing over and ignoring the impact of psychosis is indicative of difficulties functioning and integrating. The current findings indicate that young people who have increased opportunities to make sense of and explore their parent's psychosis demonstrate an increased understanding and acceptance and are better able to connect with the process of individuation. Thus, this theory adds explanatory power to the current model, highlighting the importance of young people having information and the opportunity to explore and better understand parental psychosis.

Although having more information regarding PMI is acknowledged as important within existing literature (Fredman & Fuggle, 2000; Gladstone et al., 2011) the current study adds to this by shedding light on the type of information young people require. Findings emphasise the positive impact of young people having appropriate information about their parent's illness on their ability to balance caring for and/or living with their parent with individuation. Appropriate information reduces worries, fears and confusion associated with psychosis, enabling young people to better connect with their role of being a teenager. Conversely, for some participants having information is associated with a desire to help and promote their parent's "recovery". This potentially increases feelings of responsibility, having a

negative impact on their ability to individuate from their parent. Given this, the way in which information is shared is paramount and is discussed further in the context of clinical implications. Furthermore, one of the key barriers to young people receiving information, support and speaking to others is perceiving adults to consider them as too young. Given that staff anxiety in approaching and speaking with young people appeared to be a significant barrier to recruitment, this corroborates perceptions conveyed within the data and emphasises the need for this to be addressed.

Clinical Implications

Despite existing literature emphasising the need for better identification of and supports for families affected by PMI, benefits of providing psychoeducation and better joint working between child and adult services and across agencies (e.g., Gladstone et al., 2011; Tabak et al., 2016), current findings suggest that this is not being translated to practice and too little is being done to support young people and their families. As discussed, the current model offers a unique insight into young people's experiences, thus, implications for practice are guided by their experiences and perception of needs. Young people's frustration of being perceived as too young by adults and often having limited access to appropriate information is highlighted within current findings. While this is most likely a result of adults seeking to "protect" young people, findings indicate that not sharing relevant and appropriate information with young people is actually more problematic and leaves young people feeling invalidated, overlooked and isolated. By acknowledging young people's perception of their importance in relation to their parent's support network and recognising the need for appropriate information sharing in negotiating this role in the context of adolescence, the current model offers a conceptualisation of

information sharing that remains congruent with young people's needs as opposed to dismissing the reality of their experiences. The underlying message and essence of the model is therefore paralleled with recovery models for psychosis; promoting living alongside and having an opportunity to explore these experiences rather than "sealing over" or ignoring the impact.

Better guidelines and training regarding how to share information with young people and the type of information they require would hope to increase confidence and eradicate myths regarding the perceived damaging implications of information sharing. Findings suggest that while generic information can help normalise psychosis, young people value information specific to their parent's presentation, particularly in relation to causes, triggers and maintaining factors. Given the central role of young people's perception of their parent's needs and supports on establishing a role in the context of their parent's care and individuation, facilitating their understanding of the nature of psychosis through a formulation based approach, increasing awareness of factors that may be influential in its management, and promoting awareness of parental supports is likely to be of benefit. This would also hope to reduce feelings of responsibility and promote ways of managing living with parental psychosis rather than young people perceiving a role in improving outcomes for their parent. Given that young people often report being present during crises and value information regarding management of this, ensuring they are aware of established safety plans and/or relevant contacts is likely to be beneficial. Whether perceiving a role in their parent's care or not, most young people noted feeling cautious around their parent which often led them to feeling disconnected and unsure about how best to communicate with them, thus potentially making them vulnerable

to attachment difficulties and problems individuating. Given what is known about the impact of psychosis on communication within families (Hooley, 1985; Vaughn & Leff, 1976), promotion of communication skills is also likely to be of benefit.

Given the potential benefits of providing a formulation based approach to information sharing, involving young people in the development of safety plans, promoting awareness of supports within services and facilitating communication within families, including young people in family interventions for psychosis is an obvious solution to promoting their understanding and providing supports.

Considering that clinical guidelines already recommend family interventions in order to improve outcomes for people with experience of psychosis (NICE, 2014a, 2014b; SIGN, 2013), including offspring is also likely to be a cost effective way of delivering an intervention for the potential benefit of both children and their parents. Future research will likely benefit from further exploration of outcomes for young people included in family interventions for psychosis. In view of the fact that many young people expressed mixed feelings in relation to living with and/or caring for their parent and were often reluctant to discuss these feelings with others (in particular, with their parent), these findings perhaps lend themselves to a psychodynamic interpretation around hidden feelings (i.e. children not wanting to burden parents with strong emotions). Interventions that promote expression of these underlying emotional experiences, self-compassion, normalisation and social supports are likely to be of benefit.

Given the familial predisposition and intergenerational factors associated with the development of psychosis (Baron et al., 1982; Maier et al., 1993; Marenco & Weinberger, 2000; Mortensen et al., 2003), providing better support to families

affected by psychosis remains pertinent to improving longer term outcomes. Findings highlight the potential impact of parental psychosis on adolescent development which has implications for young people's own mental health and wellbeing. They indicate that facilitating young people's access to support and information (for example, through discussion and inclusion in family interventions) is likely to promote individuation. Preventing young people from having relevant information exacerbates their fears and concerns about their parent, thus hampering their ability to individuate and having implications for their own development. Psychologically informed services promoting positive attachment relationships and individuation through empowering parents and recruiting additional family support (where necessary) is also likely to benefit outcomes for young people.

Limitations and Considerations

In light of the relatively small sample size, the grounded theory is provisional in nature. While tentative claims are made, the findings are well supported by existing literature and theory, adding to the validity to the model. The relatively homogenous sample, rich data gathered and modification of the interview schedule also facilitated theoretical sufficiency (Charmaz, 2014). Despite this, although modification of interview questions sought to sufficiently explore categories, it is possible that the interview schedule in itself was influential in "forcing data" and giving the impression of theoretical sufficiency. Given that the sample consisted of predominantly mother-daughter dyads, the finding may be less applicable to males and fathers. There are potential factors that may be unique to the mother-daughter relationship, for example, the supportive and caring nature of this relationship (as discussed in Boyd, 1989). Gender differences in emotional expression (e.g. Chaplin,

Cole, & Zahn-Waxler, 2005) and gender roles and stereotypes with regard to the acceptability of caring responsibilities may also play a role in their being potential differences in the applicability of findings to males. The evidence base would benefit from further exploration of this. The fact that parental diagnoses were not validated by parents or medical staff also introduces the possibility of an unrepresentative sample; however, eligibility screening attempted to mitigate this. Furthermore, most participants opted to discuss the research with their parents and/or close family members suggesting that those who were not eligible would be identified through this process. Although the findings indicate many similarities with existing PMI research, they also suggest that parental psychosis may pose unique challenges and opportunities to young people. Given that the majority of the sample identified themselves as having a parent with experience of bipolar disorder (including psychosis), it may be that some aspects of the findings may indicate factors that are diagnostic specific. For example, young people reflected on the often unpredictable and rapid mood changes of their parent and it may be that this is reflective of the nature of bipolar disorder as opposed to other mental health difficulties including psychosis (such as schizophrenia-type disorders). Although such reflections were not made specifically by participants with a parent with experience of bipolar disorder, given the lack of representation of other mental health difficulties, it was not possible to differentiate whether or not this was in fact diagnosis specific.

A constructivist approach to grounded theory acknowledges the researcher influences in connecting with participants and data and is therefore considered to be an important factor in interpreting findings. The role of the researcher as an NHS worker is also considered in terms of how this may have played a part in influencing

participants' responses. Despite this, memo-writing served as a helpful tool in facilitating awareness of pre-existing ideas. An example of this is evidenced through the researcher's engagement in memo-writing regarding information sharing and the evolution of preconceptions as data collection and analysis progressed (Memo 3, Appendix F). The possible influence of developmental factors on young people's perception of themselves as having a major role in their parent's care and support network is also considered. Adolescent egocentrism (Elkind, 1967) is suggestive of a difficulty in adolescents distinguishing between their own perception of how others see them and how they are actually perceived by others. While this may have skewed participants' perception of themselves in the context of their parent's care, the researcher remained aware of this possibility and the interview schedule was amended in order to seek concrete examples of caring responsibilities in order to further explore this. In most cases, young people's perception of their caring and supportive role appeared accurate.

Conclusion

In the current context of community care for psychosis, the findings facilitate our understanding of how young people with a parent with experience of psychosis conceptualise themselves in relation to their parent's care and services. The model extends our understanding of the impact of PMI on adolescent development and the unique opportunities and challenges young people face having a parent with experience of psychosis. Given the lack of existing research in this field and with young people themselves, this provides an up-to-date account of their experiences which is important in informing services and interventions. Although provisional in nature, the model is well supported by existing literature and theory. It has

implications for theory development through offering: (a) a tentative explanation of how young people establish and balance their roles in relation to parental psychosis and adolescence, and (b) an understanding of factors that may facilitate or challenge this process. In terms of clinical implications, findings reiterate the need for better identification and supports for young people and their families and the role of family focused interventions. The model indicates a need for sharing appropriate information with young people regarding their parent's presentation and management of psychosis (that is specific and formulation based) and highlights potential implications of young people not receiving this. Findings suggest that young people perceive adults' reluctance to speak with them to play a significant role here. While, understandably, this may be driven by adults' intention to protect young people, the findings indicate that this may in fact cause more difficulties for them in the long term. The current model is unique in shining a light on young people's lived experiences and realities and highlights the benefit of adults recognising and validating these experiences in order to provide appropriate information and support; thus, facilitating young people's engagement with individuation alongside connecting with and living with their parent.

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Thesis Appendices

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Appendix A. Author guidelines for Clinical Psychology Review (relevant information)

Full guidelines available at:

https://www.elsevier.com/wps/find/journaldescription.cws_home/652?generatepdf=true

Relevant excerpts have been taken from the above website.

Summary of guidelines removed for copyright purposes

Appendix B.

Reviewer:
Date:
Paper title:
First author:
Year:
Journal, volume, pages:
Research design:
Independent variables:
Dependent variables:
Main research questions / hypotheses:
Secondary research questions / hypotheses (if applicable):
Research approach for each question:
Statistical analyses:

RISK OF BIAS / INTERNAL VALIDITY
<p>1) Potential confounding variables are identified and taken into account in the design and analysis.</p> <p>Well-covered (2): The paper indicates which potential confounders have been considered, and how they have been assessed or allowed for in the analysis. Clinical judgement should be applied to consider whether all likely confounders have been considered.</p> <p>Adequately addressed (1): The paper indicates potential confounders but does not acknowledge if/how these may affect results/analyses.</p> <p>Poorly addressed (0): The paper does not address possible confounding variables.</p> <p>Information not reported/available (0)</p>
<p>2) Where relevant, an appropriate comparison group was used.</p> <p>Well-covered (2): Participants in both groups were recruited from the same population and during the same period of time and assignment to groups was randomised AND the control group is considered suitable for the purpose of this review.</p> <p>Adequately addressed (1): Participants in both groups were recruited from the same population and during the same period of time but assignment to groups was not randomised OR participants were randomised but the control group is not considered suitable for the purpose of this review.</p> <p>Not applicable (0): No comparison group was used.</p> <p>Not reported / available (0)</p>
<p>3) Where relevant, an attempt was made to blind those measuring main outcomes.</p> <p>Well-covered (2): Yes</p> <p>Poorly addressed (0): No</p> <p>Not reported / not relevant: (0)</p>
<p>4) The paper acknowledges and outlines participant drop out and takes this into account with regard to analyses.</p> <p>Well-covered (2): EITHER no participants dropped out OR few (less than 20%) participants dropped out AND drop out is well managed and taken into account in analyses.</p>

Adequately addressed (1): EITHER few (less than 20%) participants dropped out OR the drop-out rate was higher but well managed and taken into account in analyses.

Poorly addressed (0): The drop-rate rate was greater than 20% AND drop-out was not well managed or taken into account with regard to analyses.

Not reported / available (0)

5) Aims and hypotheses were clearly focused and outlined and outcomes were clearly defined.

Well covered (2): A clear and well defined research question/aim is specified and outcomes measured are clearly defined and appropriately address the research aims.

Adequately addressed (1): A clear and well defined research question/aim is specified but outcomes do not address the research aims.

Poorly addressed (0): A clear and well defined research question/aim is not specified. It is not possible to establish whether or not outcomes were sufficient in addressing research aims.

OUTCOME MEASURES

6) Main outcome measures used were accurate and systematically delivered.

Well-covered (2): Family outcome measures were systematically delivered AND were accurate (valid and reliable). Where multiple outcome measures were delivered, more than 75% were systematically delivered AND accurate.

Adequately addressed (1): Family outcome measures were either systematically delivered OR accurate (reliable or valid). Where multiple outcome measures were delivered, more than 75% were systematically delivered OR accurate.

Poorly addressed (0): Outcome measures were not systematically delivered nor accurate (reliable or valid). Where multiple outcome measures were delivered, more than 25% of outcome measures were not systematically delivered or accurate.

Not reported / available (0)

7) Where outcomes were gathered from children and young people, methods and measures were developmentally appropriate.

Well-covered (2): All outcome measures for children and young people were developmentally appropriate and where necessary, methods for gathering outcomes were adapted to consider the needs of this population.

<p>Adequately addressed (1): Only some outcome measure used were developmentally appropriate. Where necessary, methods for gathering outcomes were adapted to consider the needs of this population.</p> <p>Poorly addressed (0): Outcome measures used for children and young people were not developmentally appropriate.</p> <p>Not reported / available (0)</p> <p>Not applicable (0): Outcomes were not gathered from children or young people.</p>
<p>8) A follow-up evaluation was conducted to determine longer term outcomes.</p> <p>Well-covered (2): A follow-up evaluation was conducted. The number of people lost to follow up were outlined and this was considered within analyses where necessary.</p> <p>Adequately addressed (1): A follow-up evaluation was conducted but the number of people lost to follow-up was either not outlined or not considered within analyses (where necessary).</p> <p>Poorly addressed (0): A follow-up evaluation was not conducted.</p>
<p>STATISTICAL ISSUES</p>
<p>9) The analyses used to assess the main outcomes were appropriate.</p> <p>Well-covered (2): Analyses were appropriate given the method used and type of data outcomes gathered.</p> <p>Adequately addressed (1): All the main analyses were appropriate but some subsidiary analyses were not appropriate.</p> <p>Poorly addressed (0): Most of the analyses were not appropriate.</p>
<p>10) The study demonstrated sufficient power and sample size.</p> <p>Well-covered (2): A power analysis was conducted prior to commencement and the sample size was adequate (at least 0.8 where effect size was anticipated to be medium and alpha was 0.05).</p> <p>Adequately addressed (1): A priori power analysis was not conducted but the sample size was sufficient (according to power analyses conducted by the reviewer retrospectively).</p> <p>Poorly addressed (0): Either there was no attempt to estimate power and sample size was not adequate or a power analysis was conducted but the sample size was not adequate.</p>

REPLICABILITY OF INTERVENTION

11) The intervention demonstrated a sufficient level of validity.

Well-covered (2): The family intervention was:

- Manualised/followed a validated model OR
- adapted from a manualised intervention or validated model OR
- systematically developed and a sufficient level of detail was provided to enable replication **AND**
- treatment fidelity was ensured through evaluation of delivered sessions.

Adequately addressed (1):

- Manualised/followed a validated model OR
- adapted from a manualised intervention or validated model OR
- systematically developed and a sufficient level of detail was provided to enable replication.

Poorly addressed (0): The intervention was not manualised or did not follow a validated model and an insufficient level of detail was provided to enable replication. Fidelity was not considered.

EXTERNAL VALIDITY / GENERALISABILITY

12) The characteristics of family members participating in the intervention were included.

Well-covered (2): The study clearly describes all family members participating in the family intervention and provides detail about those in which outcomes were measured. It includes details of designation of family members and their sex, i.e. sibling and female. It includes both information about the individual with experience of psychosis and their family members.

Adequately addressed (1): The study provides some details about family members but does not include all necessary details to establish their designation and sex. The study fails to provide information about both those that participated in the intervention and those in which outcomes were measured.

Poorly addressed (0): The study does not provide sufficient detail to establish who was involved in the intervention or from whom the outcomes were measured.

13) The staff, setting and duration of the intervention was representative of routinely administered family interventions.

Well-covered (2): The intervention was:

- Carried out in an appropriate setting (for example, at home, in a clinic or hospital);
- representative of the number of sessions typically delivered and
- delivered by staff trained in the intervention.

Adequately addressed (1): The intervention met only one or two of the above criteria.

Poorly addressed (0): The intervention failed to meet the criteria outlined above and no attempt was made to deliver the intervention in a way that was representative of routine delivery of family intervention for schizophrenia / psychosis.

Not reported / available (0)

Quality assessment criteria were generated in view of recommendations by the Centre for Reviews and Dissemination (CRD) Guidance (CRD, 2009) and were informed by the checklist for measuring quality for randomised and non-randomised studies (Downs & Black, 1998) and checklists developed by SIGN (2015).

Appendix C. Table of excluded papers (at full text stage) (n = 24 papers; 19 studies). Eight papers reported outcomes over three studies¹²³

Reason for exclusion (n refers to papers)	Excluded studies (full reference)	Brief description of study (of non-English papers)
Full text unavailable in English (n = 9)	Huang, M., & Shi, Y. B. (2004). Effect of family intervention on rehabilitation of patients with schizophrenia. <i>Chinese Journal of Clinical Rehabilitation</i> , 8, 2818-1819.	Controlled trial (exp.: n = 118; control: n = 127) of FI. Psychological state of relatives measured. Depressive & anxious emotions significantly reduced in FI (p<0.05).
	Lacruz, M., Masanet, M. J., Bellver, F., Asencio, A., Ruiz, I., Iborra, M., & Montero, I. (1999). Changes in the knowledge of the key relatives about schizophrenia after a psychoeducational family intervention. <i>Archivos de Neurobiologia</i> , 62, 49-64.	Aimed to assess knowledge following FI. Most significant increase in awareness of diagnosis, symptoms, aetiology and management. Noted that a significant percentage of participants maintained initial level of knowledge.
	Mak, K. Y., Wong, M. C., Ma, L. K., & Fung, S. C. (1997). A cost-effectiveness study of a community-based family management rehabilitation programme for schizophrenic outpatients in Hong Kong: a six-month report. <i>Hong Kong Journal of Psychiatry</i> , 7, 26-35.	BFT vs. control. Outcomes measured at 6m. Preliminary data indicates BFT increases knowledge about illness in family members.
	Montero, I., Masanet, M. J., Lacruz, M., Bellver, F., Asencio, A., & Garcia, E. (2006). Family intervention in schizophrenia: long-term effect on main caregivers. <i>Actas espanolas de psiquiatria</i> , 34, 169-174.	5 year follow-up. Psychological distress measured using GHQ. Significant reduction in distress between baseline and 5 year follow up.
	Shi, Y., Zhao, B., Dongsheng, X. & Sen, J. (2000). A compared study of life quality in schizophrenic patients after family intervention. <i>Chinese Mental Health Journal</i> , 14, 135-137.	FI delivered over 2 years. Improvements in quality of life of family members following FI.

	<p>Veltro, F., Magliano, L., Morosini, P., Fasulo, E., Pedicini, G., Cascavilla, I., & Falloon, I. (2006). Randomised controlled trial of a behavioural family intervention: 1 year and 11-years follow-up. <i>Epidemiologia e Psichiatria Sociale</i>, 15, 44-51.</p> <p>Ramírez, A., Palacio, J. D., Vargas, C., Díaz-Zuluaga, A. M., Duica, K., Agudelo, B. Y., ...López-Jaramillo, C. (2017). Expressed emotions, burden and family functioning in schizophrenic and bipolar I patients of a multimodal intervention program: PRISMA. <i>Revista Colombiana de Psiquiatría</i>, 46, 2-11.</p> <p>¹Zhao, B. (1999). Comparative Study on Family Intervention on Schizophrenics in Community. <i>Chinese Mental Health Journal</i>, 13, 324-324.</p> <p>¹Zhao, B., Shi, J., & Shen, Y. (2000). Family intervention of chronic schizophrenics in community: A follow-up study. <i>Chinese Mental Health Journal</i>, 14, 283-285.</p>	<p>RCT: 11 year follow-up. Assessment of burden. Significantly reduced following FI, no reduction at follow-up.</p> <p>Prospective, longitudinal, therapeutic-comparative study was conducted with 302 patients (104 schizophrenic and 198 bipolar patients) who were randomly assigned to a multimodal intervention (MI) program PRISMA or traditional intervention (TI). MI group received care from psychiatry, general medicine, neuropsychology, family therapy, and occupational therapy. TI group received care from psychiatry and general medicine. The study did not show changes in variables of burden or family functioning between bipolar and schizophrenic groups that were under TI vs MI.</p> <p>Controlled trial. Family burden measured. 2 year follow up measured anxiety (Zhao et al., 2000)</p>
Duration of family intervention less than 10 sessions (n = 8)	<p>Bertrando, P., Cecchin, G., Clerici, M., Beltz, J., Milesi, A., & Cazzullo, C. L. (2006). Expressed emotion and Milan systemic intervention: A pilot study on families of people with a diagnosis of schizophrenia. <i>Journal of Family Therapy</i>, 28, 81-102.</p> <p>²Clarkin, J. F., Glick, I. D., Haas, G. L., Spencer, J. H., Lewis, A. B., Peyser, J., ...Lestelle, V. (1990). A randomized clinical trial of inpatient family intervention V. Results for affective disorders. <i>Journal of Affective disorders</i>, 18, 17-28.</p>	

	<p>²Glick, I. D., Clarkin, J. F., Haas, G. L., Spencer, J. H., & Chen, C. L. (1991). A randomized clinical trial of inpatient family intervention: VI. Mediating variables and outcome. <i>Family Process</i>, 30, 85-99.</p> <p>²Glick, I. D., Clarkin, J. F., Haas, G. L., & Spencer Jr, J. H. (1993). Clinical significance of inpatient family intervention: conclusions from a clinical trial. <i>Psychiatric Services</i>, 44, 869-873.</p> <p>²Glick, I. D., Spencer, J. H., Clarkin, J. F., Lewis, A. B., Peyser, J., DeMane, N., ...Lestelle, V. (1990). A randomized clinical trial of inpatient family intervention IV. Followup results for subjects with schizophrenia. <i>Schizophrenia Research</i>, 3, 187-200.</p> <p>³Ran, M. S., Xiang, M. Z., Chan, C. L. W., Leff, J., Simpson, P., Huang, M. S., ...Li, S. G. (2003). Effectiveness of psychoeducational intervention for rural Chinese families experiencing schizophrenia. <i>Social Psychiatry and Psychiatric Epidemiology</i>, 38, 69-75.</p> <p>³Ran, M. S., Chan, C. W., Ng, S. M., Guo, L. T., & Xiang, M. Z. (2015). The effectiveness of psychoeducational family intervention for patients with schizophrenia in a 14-year follow-up study in a Chinese rural area. <i>Psychological Medicine</i>, 45, 2197-2204.</p> <p>Retzer, A., Simon, F. B., Weber, G., Stierlin, H., & Schmidt, G. (1991). A followup study of manic-depressive and schizoaffective psychoses after systemic family therapy. <i>Family Process</i>, 30, 139-153</p>
Family intervention excluded the family member with psychosis (n = 3)	<p>Barrowclough, C., Tarrier, N., Lewis, S., Sellwood, W., Mainwaring, J., Quinn, J., & Hamlin, C. (1999). Randomised controlled effectiveness trial of a needs-based psychosocial intervention service for carers of people with schizophrenia. <i>The British Journal of Psychiatry</i>, 174, 505-511.</p> <p>Kulhara, P., Chakrabarti, S., Avasthi, A., Sharma, A., & Sharma, S. (2009). Psychoeducational intervention for caregivers of Indian patients with schizophrenia: a randomised-controlled trial. <i>Acta Psychiatrica Scandinavica</i>, 119, 472-483.</p>

	Smith, J. V., & Birchwood, M. J. (1987). Specific and non-specific effects of educational intervention with families living with a schizophrenic relative. <i>The British Journal of Psychiatry</i> , 150, 645-652.
Intervention included group intervention / MFT (without method of controlling for this) (n = 3)	<p>Addington, J., McCleery, A., & Addington, D. (2005). Three-year outcome of family work in an early psychosis program. <i>Schizophrenia Research</i>, 79, 107-116.</p> <p>Masanet, M., Montero, I., Lacruz, M., Bellver, F., & Hernández, I. (2007). Long-term outcome of family therapy in schizophrenia. <i>Clinical Schizophrenia & Related Psychoses</i>, 1, 168-174.</p> <p>Xiong, W., Phillips, M. R., Hu, X., Wang, R., Dai, Q., Kleinman, J., & Kleinman, A. (1994). Family-based intervention for schizophrenic patients in China. A randomised controlled trial. <i>The British Journal of Psychiatry</i>, 165, 239-247.</p>
Outcomes for family members not available post intervention (n = 1)	Martínez, J. A. M., & García, J. F. G. (2001). Family intervention programme in schizophrenia: two-year follow-up of the Andalusia study. <i>Apuntes de Psicología</i> , 3, 421-430.

Note: FI = family intervention

Appendix D. Table of outcome measures (including full references)

Category	Outcome	Outcome measure	Full reference (or citation of paper including outcome measure where full reference unknown).
Wellbeing	Burden	The Subjective Distress Scale	Falloon, I. R. H., Magliano, L., Graham-Hole, V., & Woodroffe, R. (1996). The stress of caring for disabling mental disorders in a home-based rehabilitation service. <i>The Journal of Nervous and Mental Disease</i> , 184, 381-383.
		Family Problems Questionnaire	Morosini P, L., Roncone, R., Veltro, F., Palomba, U., & Casacchia, M. (1991). Routine assessment tool in psychiatry: The questionnaire of family attitudes and burden. <i>Italian Journal of Psychiatry and Behavioural Sciences</i> , 1, 95–101.
		Family Burden Interview	Pai, S., & Kapur, R. L. (1981). The burden on the family of a psychiatric patient: Development of an interview schedule. <i>The British Journal of Psychiatry</i> , 138, 332-335.
		Social Adjustment Scale (modified)	Schooler, N., Hogarty, G., & Weissman, M. (1979) <i>as cited by</i> Mueser, K. T., Gingerich, S. L., & Rosenthal, C. K. (1994). Educational family therapy for schizophrenia: A new treatment model for clinical service and research. <i>Schizophrenia Research</i> , 13, 99-107.
		Social Behaviour Assessment Scale	Platt, S., Weyman, A., Hirsch, S., & Hewett, S. (1980). The Social Behaviour Assessment Schedule (SBAS): Rationale, contents, scoring and reliability of a new interview schedule. <i>Social Psychiatry</i> , 15, 43-55.
		Assessment of Burden Interview	MacCarthy, B., Lesage, A., Brewin, C. R., Brugha, T. S., Mangen, S., & Wing, J. K. (1989). Needs for care among the relatives of long-term users of day care: A report from the Camberwell High Contact Survey. <i>Psychological Medicine</i> , 19, 725-736.

	Burden Assessment Scale	Reinhard, S. C., & Horwitz, A. V. (1994). Burden assessment scale for families of the seriously mentally ill. <i>Evaluation and Program Planning, 17</i> , 261-269.
Psychological distress (including mental health / 'psychological symptoms', guilt & shame)	General Health Questionnaire-28	Goldberg, D. (1978). <i>Manual of the general health questionnaire</i> . NFER Nelson.
	Self-conscious Emotions for Schizophrenia Scale	Weisman de Mamani, A. G., Kymalainen, J.A., Rosales, G.A., & Armesto, J.C. (2007). Expressed emotion and interdependence in White and Latino / Hispanic family members of patients with schizophrenia. <i>Psychiatry Research, 151</i> , 107-113.
	Hopkins Symptom Checklist	Derogatis, L. R., Lipman, R. S., Rickels, K., Uhlenhuth, E. H., & Covi, L. (1974). The Hopkins Symptom Checklist (HSCL): A self-report symptom inventory. <i>Behavioral Science, 19</i> , 1-15.
Coping	Family Coping Questionnaire	Magliano, L., Guarneri, M., Marasco, C., Tosini, P., Morosini, P. L., & Maj, M. (1996). A new questionnaire assessing coping strategies in relatives of patients with schizophrenia: Development and factor analysis. <i>Acta Psychiatrica Scandinavica, 94</i> , 224-228.
	Rating of verbal report	<i>As outlined in</i> Falloon, I. R. H., & Pederson, J. (1985). Family management in the prevention of morbidity of schizophrenia: The adjustment of the family unit. <i>British Journal of Psychiatry, 147</i> , 156-163.
Quality of life	World Health Organisation Quality of Life (WHOQoL)Assessment	WHOQoL Group, T. W. (1998). The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties. <i>Social Science & Medicine, 46</i> , 1569-1585.
Inter-dependence	Self-Conscious Emotions for Schizophrenia Scale	Singelis, T.M. (1994). The measurement of independent and interdependent self construals. <i>Personality and Social Psychology Bulletin, 20</i> , 580-591

Family Interactions	Expressed emotion	Camberwell Family Interview	Leff, J. P., & Vaughn, C. E. (1985). <i>Expressed emotion in families</i> . New York: Guilford Press.
		Five Minute Speech Sample	Magaña, A. B., Goldstein, M. J., Karno, M., Miklowitz, D. J., Jenkins, J., & Falloon, I. R. (1986). A brief method for assessing expressed emotion in relatives of psychiatric patients. <i>Psychiatry Research</i> , 17, 203-212.
		Family Questionnaire	Wiedemann, G., Rayki, O., Feinstein, E., & Hahlweg, K. (2002). The Family Questionnaire: Development and validation of a new self-report scale for assessing expressed emotion. <i>Psychiatry Research</i> , 109, 265-279.
	Affective style, family functioning, family climate (conflict), family attitude	FAM-III – Dyadic Relationships Scale	Skinner, H. A., Steinhauer, P. D., & Santa-Barbara, J. (2009). The family assessment measure. <i>Canadian Journal of Community Mental Health</i> , 2, 91-103.
		Frequency of Conflict Questionnaire	As outlined in Zastowny, T. R., Lehman, A. F., Cole, R. E., & Kane, C. (1992). Family management of schizophrenia: A comparison of behavioral and supportive family treatment. <i>Psychiatric Quarterly</i> , 63, 159-186.
		Interaction Task (affective style categorised)	As outlined in Doane, J. A., Falloon, I. R., Goldstein, M. J., & Mintz, J. (1985). Parental affective style and the treatment of schizophrenia: Predicting course of illness and social functioning. <i>Archives of General Psychiatry</i> , 42, 34-42.
		Dyadic Interaction Encounter	As outlined in Girón, M., Nova-Fernandez, F., Mana-Alvarenga, M., Nolasco, A., Molina-Habas, A. Fernandez-Yanez, A., ...Gomez-Beneyto, M. (2015). How does family intervention improve outcome of people with schizophrenia? <i>Social Psychiatry & Psychiatric Epidemiology</i> , 5, 379-387.

		Patient Rejection Scale	Kreisman, D., Blumenthal, R., Borenstein, M., Woerner, M., Kane, J., Rifkin, A., & Reardon, G. (1988). Family attitudes and patient social adjustment in a longitudinal study of outpatient schizophrenics receiving low-dose neuroleptics: The family's view. <i>Psychiatry</i> , 51, 3-13.
Knowledge and Skills	Knowledge	Knowledge Interview	Berkowitz, R., Eberlein-Fries, R., Kuipers, L., & Leff, J. (1984). Educating relatives about schizophrenia. <i>Schizophrenia Bulletin</i> , 10, 418-429.
		Knowledge About Schizophrenia Inventory	Barrowclough, C., Tarrier, N., Watts, S., Vaughn, C., Bamrah, J. S., & Freeman, H. L. (1987). Assessing the functional value of relatives' knowledge about schizophrenia: A preliminary report. <i>The British Journal of Psychiatry</i> , 151, 1-8.
		The Knowledge Test	<i>As outlined in</i> Mueser, K. T., Gingerich, S. L., & Rosenthal, C. K. (1994). Educational family therapy for schizophrenia: A new treatment model for clinical service and research. <i>Schizophrenia Research</i> , 13, 99-107.
		The Mental Illness Questionnaire	<i>As outlined in</i> Zastowny, T. R., Lehman, A. F., Cole, R. E., & Kane, C. (1992). Family management of schizophrenia: A comparison of behavioral and supportive family treatment. <i>Psychiatric Quarterly</i> , 63, 159-186.
	Problem solving	Interaction Task (problem solving style assessed)	<i>As outlined in</i> Doane, J. A., Falloon, I. R., Goldstein, M. J., & Mintz, J. (1985). Parental affective style and the treatment of schizophrenia: Predicting course of illness and social functioning. <i>Archives of General Psychiatry</i> , 42, 34-42.
		Family Problem Discussion	<i>As outlined in</i> Zastowny, T. R., Lehman, A. F., Cole, R. E., & Kane, C. (1992). Family management of schizophrenia: A comparison of behavioral and supportive family treatment. <i>Psychiatric Quarterly</i> , 63, 159-186.

		Family Problem Solving Task	Bellack, A. S., Haas, G. L., & Tierney, A. M. (1996). A strategy for assessing family interaction patterns in schizophrenia. <i>Psychological Assessment</i> , 8, 190-199
	Communication skills	Family Problem Solving Task	Bellack, A. S., Haas, G. L., & Tierney, A. M. (1996). A strategy for assessing family interaction patterns in schizophrenia. <i>Psychological Assessment</i> , 8, 190-199
		Family Problem Discussion	As outlined in Zastowny, T. R., Lehman, A. F., Cole, R. E., & Kane, C. (1992). Family management of schizophrenia: A comparison of behavioral and supportive family treatment. <i>Psychiatric Quarterly</i> , 63, 159-186.
Support	Perception	Social Network Questionnaire	Magliano, L., Fadden, G., Madianos, M., de Almeida, J. C., Held, T., Guarneri, M.,...Maj, M. (1998). Burden on the families of patients with schizophrenia: results of the BIOMED I study. <i>Social psychiatry and psychiatric epidemiology</i> , 33, 405-412.
	Awareness	Community Resources Scale	As outlined in Zastowny, T. R., Lehman, A. F., Cole, R. E., & Kane, C. (1992). Family management of schizophrenia: A comparison of behavioral and supportive family treatment. <i>Psychiatric Quarterly</i> , 63, 159-186.
	Social resources / functioning	Social Adjustment Scale-Self Report	Weissman, M. M., Prusoff, B. A., Thompson, W. D., Harding, P. S., & Myers, J. K. (1978). Social adjustment by self-report in a community sample and in psychiatric outpatients. <i>The Journal of Nervous and Mental Disease</i> , 166, 317-326.
		Social Network Questionnaire	Magliano, L., Fadden, G., Madianos, M., de Almeida, J. C., Held, T., Guarneri, M.,...Maj, M. (1998). Burden on the families of patients with schizophrenia: results of the BIOMED I study. <i>Social psychiatry and psychiatric epidemiology</i> , 33, 405-412.

Experience of Caregiving	Appraisal of Caregiving	Experience of Caregiving Inventory	Szmukler, G. I., Burgess, P., Herrman, H., Bloch, S., Benson, A., & Colusa, S. (1996). Caring for relatives with serious mental illness: the development of the Experience of Caregiving Inventory. <i>Social Psychiatry and Psychiatric Epidemiology</i> , 31, 137-148.
	Attitude towards Caring	Subjective Attitude Scale	Falloon, I. R. H., Magliano, L., Graham-Hole, V., & Woodroffe, R. (1996). The stress of caring for disabling mental disorders in a home-based rehabilitation service. <i>The Journal of Nervous and Mental Disease</i> , 184, 381-383.

Appendix E. Author guidelines for Qualitative Psychology (relevant information)

Full guidelines available at: <http://www.apa.org/pubs/journals/qua/?tab=4>

Summary of guidelines removed for copyright reasons.

Appendix F. Memos (1, 2 & 3)

(1) Memo 1 (researcher perspective and theoretical orientation).....	p.169
(2) Memo 2 (experience of recruitment / being perceived as too young).....	p.170
(3) Memo 3 (information).....	p.173

Appendix F (1). Memo 1. Researcher perspective and theoretical orientation

Memo - Theoretical orientation – July 2014

Where do I position myself in the context of this study? What are the issues that may impact on my perception of a young person's 'reality' or experience? In line with the concept of constructivism, my position on reality is that this can only really be perceived and constructed in relation to contexts, constructs and relationships. The reality 'created' depends on who is experiencing it, how they are experiencing it, how they are communicating it and who is hearing it. Charmaz argues that there is no real world to be discovered but that the world is made real in the minds and through the words and actions of those experiencing it. There will, however, likely be commonalities across these experiences. So, I am part of the construction of the 'reality' of living with parental psychosis. I bring to this my own pre-conceptions, experiences, knowledge and language. Firstly, having completed a literature review for the purpose of building a protocol, I am aware of the current influences of PMI on young people. Literature suggests that young people would like to be better informed about their parent's illness and this helps them to make sense of and cope with PMI. Young people are often considered 'invisible' to services and frequently have caring responsibilities. I also work with adults with experience of psychosis (some of which are parents), and deliver family interventions alongside other clinicians (who carry their own perceptions). I need to be aware of the potential impact of this prior knowledge and experience when exploring young people's perceptions and realities. I am likely to bring my own interpretation on the material presented and as such may pursue lines of enquiry that seem relevant to me. This will also likely be informed by the emotional content and participant reactions to interview questions. I am mindful of the potential power imbalance that may be perceived by young people: the fact that I am older, am in a position of 'researcher', 'clinician', 'trainee', female....these are all factors that may influence young people's disclosures. It is going to be important for me to balance this potential power imbalance by ensuring that young people feel as in control and comfortable as possible. Where possible, I will meet them in a place that they choose and feel comfortable in and meet them at a time that suits them. I will highlight their role in giving feedback in order to improve experiences for other young people and to inform my interview skills. Allowing young people to take the lead in discussion as much as possible fits with grounded theory and allows them a better sense of control and agency – guiding me to explore issues that are important to them. Making sure that I am continually 'checking out' what young people mean and providing them with an opportunity to let me know if I've misunderstood/misinterpreted by summarising and feeding back will be important in remaining as close to their reality as possible.

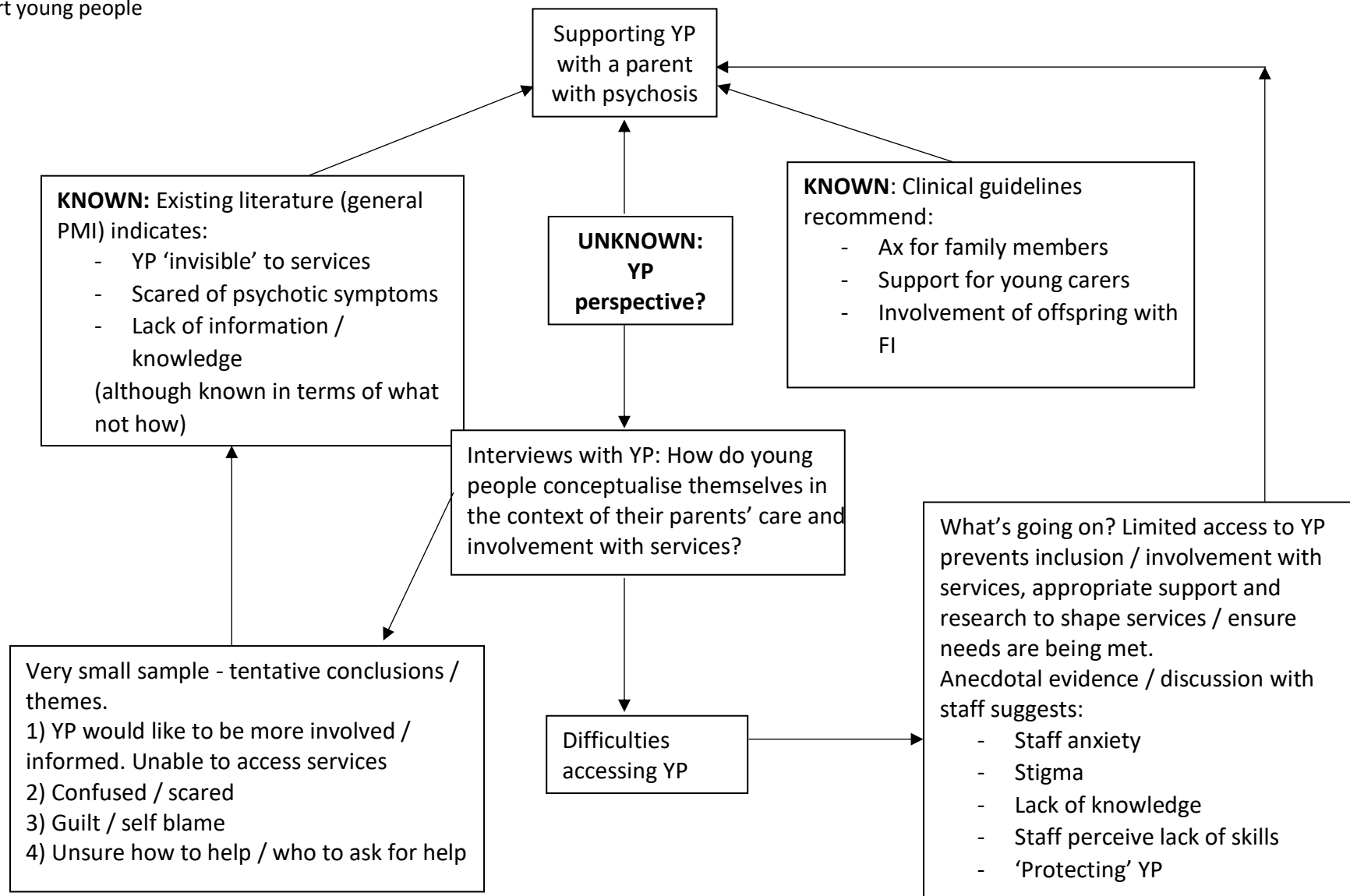
Appendix F (2). Memo 2. Experience of recruitment / being perceived as too young

Memo – Experiences of recruitment – August, 2016

Recruitment barriers

The literature indicates that young people are often invisible to services and their needs are frequently unmet. We know that they require more information and involvement with their parent's care but this requires good joined up working and support from the wider service network. Literature suggests that over half of people with a diagnosis of a psychotic disorder are parents and the scoping exercise prior to starting the research suggested that third sector services were in a good position to identify eligible participants/parents. So, what factors are contributing to recruitment difficulties? While management staff seem to be supportive of the research and are able to identify with the rationale and importance of the research question, this doesn't always seem to be the case for frontline staff. Having met with a number of organisations over the past year, this seems to be a common theme. When attending meetings, I have often been met with reluctance and negative attitudes from staff – feeling concerned about speaking with young people regarding issues they deem to be sensitive. This absolutely seems to be coming from a place of care and from adults seeking to protect young people; however, in doing so, we seem to be losing out on an opportunity to seek their views and properly understand their experiences. The reluctance of speaking with young people has surprised me. It has been interesting to note that after discussion with staff and outlining the rationale and importance of getting views from young people, staff have been more willing to approach young people, yet there seems to be a great deal of concern about how to broach the subject with young people and how to raise the research with them. I wonder how these messages might impact on young people. I wonder whether through not talking there is an implicit message that young people shouldn't be talking about their experiences. I wonder whether this then feeds in to stigma associated with mental health and young people's reluctance to speak with others. Through struggling with this perception from some adults, I am stumbling across the very phenomena that I would like to study! How do we get around this?!

Memo – Barriers to recruitment – August, 2016: Diagram linking recruitment issues back to research question and ‘unknowns’ regarding how to support young people



Memo - Recruitment barriers / feeling too young - November 2016

Feeling like adults see them as being too young to receive information about their parent seems to be a common theme within interviews and seems to be playing out in the recruitment process too. It would be useful to get a better sense of young people's views about this. What do they think is behind this? How do they perceive adults? What have their experiences in talking to adults been? What's gone well? What's not gone well?

Memo - Feeling too young - February 2017

Young people seem to have strong views about adults not talking and feeling too young. There seems to be a theme around experiences of being perceived at risk by adults and a worry about disclosing information that may be perceived as putting them at risk. Young people seem to perceive adults to view them as too young to have information. Themes around thinking that adults worry about causing upset or that they wouldn't understand seem to be prevalent.

Appendix F (3). Memo 3. Information

Memo December 2016 – Information – Challenging preconceptions

Having interviewed five participants, there seems to be a theme emerging with regard to the usefulness of having information. Young people seem to be able to connect better with teenage life when they know the nature of their parent's difficulties and who is around to support them. There is a sense of relief and security in having information and a better understanding. They also seem to want information in order to know how to better respond to and connect with their parent (and better understand triggers). However, while having information is frequently reported to have a positive impact on young people's understanding of parental psychosis, some young people have spoken about the want and 'need' to find out information so that they are able to help as best they can. I need to be mindful of my position here, acknowledging my own preconceptions about childhood to enable me to be open to exploring this further with young people. Despite this, I am curious about the impact of information sharing – something that I had originally perceived to be only a positive thing (given what we know from the literature) can perhaps be conceptualised as having a 'negative' influence also. Exploration of this concept is likely to be useful to further inform and build this category.

Appendix G. Example: Website pages



Young People with a Parent with Experience of Mental Illness Share Your Views

[HOME](#)[ABOUT](#)[CONTACT](#)[PARENTS / GUARDIANS](#)[USEFUL LINKS](#)



[What is the research about?](#)[What will happen if I want to take part?](#)[What will happen to my information?](#)[What are the costs / benefits?](#)[How do I take part?](#)

I am speaking with young people aged 12-18 years who have a parent with experience of mental illness including psychosis, a schizophrenia-type disorder or bipolar disorder. I am interested in who supports them, and what they want and need from others. Young people's views are extremely valuable. Hearing about their experiences can help people in health services and other organisations focus on the issues that matter to young people.

If you are aged 12-18 years and have a parent with experience of psychosis, a schizophrenia-type disorder or bipolar disorder (who you have regular contact with), you can [find out more about this research here](#).

Not sure whether you are eligible to take part? Please [click here](#).

Please note: This research is being carried out in Central and South East Scotland.

Young People with a Parent with Experience of Mental Illness

Share Your Views

[HOME](#)[ABOUT](#)[CONTACT](#)[PARENTS / GUARDIANS](#)[USEFUL LINKS](#)

Am I eligible to take part?

You can take part in the research if you are 12-18 years of age and have regular contact with a parent who has experience of [psychosis](#), a schizophrenia-type disorder or bipolar disorder.

If you are unsure whether you are eligible to take part, please [contact me](#) and I would be more than happy to talk about this with you.

Please note: This research is being carried out in Central and South East Scotland.

[HOME](#)[ABOUT](#)[CONTACT](#)[PARENTS / GUARDIANS](#)[USEFUL LINKS](#)[What is the research about?](#)[What will happen if I want to take part?](#)[What will happen to my information?](#)[What are the costs / benefits?](#)[How do I take part?](#)

FOR PARENTS / GUARDIANS

- Whilst we assume you are competent to make a decision, discussing participation with a responsible adult can help you can help your child to make an informed decision.
- If your child would like to take part, I will arrange to meet with them. Where necessary, it would be useful if you or another adult they trust could support them to attend. Travel costs to and from the meeting will be reimbursed.
- Your child may wish to bring an adult they trust in to the meeting. It would be helpful if you could support them in this.
- If your child does want to take part, it is really important that their own views are reflected. Please feel free to discuss the project with them but it would be helpful if you could try to avoid suggesting things that he / she might say.

If you have any concerns about your child's ability to make a decision about participation or have any questions about the research, please [contact me](#). You can also safely leave your contact details [here](#) and I will get back to you.

0% complete

Page 1: Contact Details

Thank you for your interest in this research. If you would like to take part or find out more, please leave your name and contact details below and I will get back to you as soon as possible.

Please note:

- Only I will be able to access your details and I will only be using them to contact you.
- You do not have to provide all contact details requested - please only leave details that you are happy for me to use in order to contact you.

1. Name:

2. Mobile phone number:

3. Home phone number:

4. Email address:

5. Home address:

Appendix H. Recruitment pack

(1) Participant information leaflet.....	p.178
(2) Parent / guardian letter (recruitment via young person).....	p.180
Parent / guardian letter (recruitment via parent).....	p.181

Please note: Appendix H (1) represents a folded A5 leaflet. Content has been re-scaled for inclusion as an appendix.

Young People with a Parent with Experience of Mental Illness* Share Your Views

*Including psychosis, schizophrenia-type disorders and bipolar disorder.

Fife Health
& Social Care
Partnership

Supporting the people of Fife together



THE UNIVERSITY
of EDINBURGH

What is the research about?

Page 2 of 4

I am speaking with young people aged 12-18 years who have a parent with experience of mental illness including psychosis, a schizophrenia-type disorder or bipolar disorder. I am interested in who supports them, and what they want and need from others. Young people's views are extremely valuable. Hearing about their experiences can help people in health services and other organisations focus on the issues that matter to young people.

Why am I being asked?

You have identified yourself as having a parent with experience of psychosis, a schizophrenia-type disorder or bipolar disorder. I would really like to meet with you and ask you about your experiences.

How to take part

- Read this information and take some time to think about whether you want to take part. It is usually best to include a parent / guardian in this decision.
- If you would like to take part, you can contact me directly or leave your contact details with the member of staff that gave you this leaflet and I will get in touch.
- When we first speak, we will have a short conversation (about 10 minutes) to make sure that you are eligible to take part. This will also give you chance to ask any questions you may have about the research.
- We will arrange a time and place to meet. This might be at an NHS venue (i.e. a hospital or a health centre), a community venue (i.e. a youth hub) or at School or College. I will do my best to arrange a time and place that best suits you.
- When we meet, we will talk about the project and I will give you a consent form to sign. This makes sure that you know what you have agreed to do.
- Once you have consented, we will have a conversation that will last about 45 minutes (depending on how much you have to say).
- I will ask you things about your involvement in your parent's care and the supports that are available to you. The exact questions will depend on what you have to say and what your experiences have been.
- You can choose to have an adult with you but I will be asking you questions about your experiences only.
- Our conversation will be audio recorded. This is to make sure that I do not miss anything!
- At any time, you can ask questions about the research, and give me feedback.

- I may want to meet with you again to ask some more questions. You can decide whether or not you would be happy to be contacted again to talk about this.
- You can also let me know whether or not you would like me to write to your GP to let them know that you have taken part in the research.

What will happen to the information I give you?

I will type up the conversation on to a computer and the recording will then be deleted from the recording device. The typed version will be kept safely and will be made anonymous. This means that there will be no way of anybody but me connecting the information to you. If you tell me something that makes me think that you are not safe (for example, that someone is hurting you), I will need to share this information with other relevant people.

Any information that includes your name / contact details will be stored securely. It will be safely destroyed after the research has been written up. When the project is written up, it will not include any information that can identify you. Nobody reading the report will be able to tell that you were involved. I may include your words but these will not be linked to any information about you.

What are the potential costs / benefits in taking part?



Talking about your experiences might be difficult but it can also be a helpful thing to do. If you do become upset at any point, you can take a break or choose to end the conversation. You can also talk to me at the end of the conversation if you are upset or if anything is bothering you. You do not have to talk about anything you do not want to.



Meeting up will take time. We can arrange a time to meet that will best suit you. Travel costs will be reimbursed.



You will receive a certificate of participation that can be used to contribute towards gaining awards such as the Duke of Edinburgh.

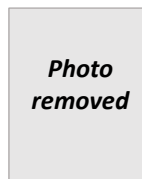
Do I have to take part?

No. It is up to you whether you take part. It is usually a good idea to involve an adult you trust in this decision. The support you receive now or in the future will not be affected in any way if you do not wish to take part. If you have any questions about the research, you

can contact me. If you decide to take part, you can change your mind at any point during our conversation and before our conversation has been typed up and made anonymous.

This research is part of my training for a Doctorate in Clinical Psychology. It has been reviewed and given a favourable ethical opinion by the South East Scotland Ethics Committee.

If you would like to take part in the research, please contact me and we can arrange a time and place to meet. You can contact me by:



Phone / Text: 07708 055127



Email: H.Wells@sms.ed.ac.uk



Website: hwells3.wix.com/research

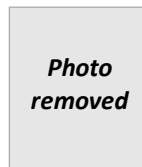


Holly Wells
Trainee Clinical Psychologist

You can also leave your contact details on the website above or with the staff member that gave you this leaflet and I will get back to you. The website also provides information about the research and has some links to organisations / supports that you may find useful.

I have some questions....

Please contact me if you have any questions. You can also contact my supervisor:



Email: Emily.Taylor@ed.ac.uk

Dr Emily Taylor
Clinical Psychologist

Thank you!

If you would like to talk to someone about this research who is not directly involved, please contact *(personal/contact details removed)*

If you wish to make a complaint about the research, please contact *(personal /contact details removed)*



Dear parent / guardian,

Research: Young people with a parent with experience of mental illness

I am talking to young people aged 12-18 years who have a parent with experience of psychosis, a schizophrenia-type disorder or bipolar disorder. I am interested in who supports them, and what they want and need from others. Young people's views are extremely valuable. Hearing about their experiences can help people in health services and other organisations focus on the issues that matter to young people.

Your child has identified themselves as being eligible to take part and should have received a participant information leaflet. This leaflet outlines details of the study. Your child does not have to take part but the leaflet will hopefully help them decide. It is usually best for a parent / guardian / responsible adult to be involved in this decision.

What can you do to help?

- Whilst we assume a young person to be able (competent) to make a decision, discussing participation with a responsible adult is always helpful. We hope that you can help them to make an informed decision.
- If your child would like to take part, I will arrange to meet with them. Where necessary, it would be useful if you or another adult they trust could support them to attend. Travel costs to and from the meeting will be reimbursed.
- Your child may wish to bring an adult they trust in to the meeting. It would be helpful if you could support them in this.
- If your child does want to take part, it is really important that their own views are reflected. Please feel free to discuss the project with them but it would be helpful if you could try to avoid suggesting things that he / she might say.

If you have any concerns about your child's ability to make a decision about participation or have any questions about the research, please contact me by:

Phone / text: 07708 055127

Email: H.Wells@sms.ed.ac.uk

Website: hwells3.wix.com/research

You can safely leave your details on the website and I will get back to you.

You can also contact my supervisor (Dr Emily Taylor) by:

Email: Emily.Taylor@ed.ac.uk

The website above also provides more information about the research and has some links to organisations / supports that may be helpful.

Many thanks in advance for your support and cooperation.

Kind regards

Holly Wells

Trainee Clinical Psychologist



Dear parent / guardian,

Research: Young people with a parent with experience of mental illness

I am talking to young people aged 12-18 years who have a parent with experience of psychosis, a schizophrenia-type disorder or bipolar disorder. I am interested in who supports them, and what they want and need from others. Young people's views are extremely valuable. Hearing about their experiences can help people in health services and other organisations focus on the issues that matter to young people.

You have identified your child as being eligible to take part and should have received a participant information leaflet to pass on to them. This leaflet outlines details of the study. Your child does not have to take part but the leaflet will hopefully help them decide. It is usually best for a parent / guardian / responsible adult to be involved in this decision.

What can you do to help?

- Whilst we assume a young person to be able (competent) to make a decision, discussing participation with a responsible adult is always helpful. We hope that you can help them to make an informed decision.
- If your child would like to take part, I will arrange to meet with them. Where necessary, it would be useful if you or another adult they trust could support them to attend. Travel costs to and from the meeting will be reimbursed.
- Your child may wish to bring an adult they trust in to the meeting. It would be helpful if you could support them in this.
- If your child does want to take part, it is really important that their own views are reflected. Please feel free to discuss the project with them but it would be helpful if you could try to avoid suggesting things that he / she might say.

If you have any concerns about your child's ability to make a decision about participation or have any questions about the research, please contact me by:

Phone / text: 07708 055127

Email: H.Wells@sms.ed.ac.uk

Website: hwells3.wix.com/research

You can safely leave your details on the website and I will get back to you.

You can also contact my supervisor (Dr Emily Taylor) by:

Email: Emily.Taylor@ed.ac.uk

The website above also provides more information about the research and has some links to organisations / supports that may be helpful.

Many thanks in advance for your support and cooperation.

Kind regards

Holly Wells

Trainee Clinical Psychologist

Appendix I: Ethics and R&D approvals

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(2) Confirmation of amendments.....	184
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(4) R&D management approval (NHS Fife).....	191
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(6) R&D management approval (NHS Forth Valley)	193

Please note: Relevant pages of approval letters are included to prevent unnecessary duplication of information. Personal /contact details have been removed.

Appendix I (1). Confirmation of approval from the University of Edinburgh Department of Clinical and Health Psychology Ethics Research Panel.



Holly Wells
Trainee Clinical Psychologist

*Personal/contact
details removed*

09 July 2015

Dear Holly,

Application for Level 2/3 Approval

Project Title: Young People with a Parent with Experience of Psychosis: How Do They Conceptualise Themselves in the Context of Their Parent's Care and Involvement with Service

Academic Supervisor: Emily Taylor

Thank you for submitting the above research project for review by the Department of Clinical and Health Psychology Ethics Research Panel. I can confirm that the submission has been independently reviewed and was approved on the 6th July 2015.

Should there be any change to the research protocol it is important that you alert us to this as this may necessitate further review.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'K Gardner'.

Kirsty Gardner
Administrator
Clinical Psychology

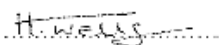
Appendix I (2). Confirmation of amendments (Department of Clinical and Health Psychology Ethics Research Panel).

Amendment 1.

Subsequent to receipt of ethical approval above, I, the applicant, would like to request the following amendment/s to my original proposal.

Since receipt of ethical approval, I have amended the consent form in relation to this research in order to document consent from participants for the publication / dissemination of findings. I have highlighted the amended section on the consent form and have attached this within an email. I would be very grateful if you would review this.

Many thanks

Signature: 

Date: 29/10/2015

I can confirm that the above amendment has been reviewed.

- a. Ethical issues have been satisfactorily addressed and no further response from the applicant is necessary.

Signature:



Position: Lecturer in Clinical Psychology, Ethics Tutor

Date: 04/11/15

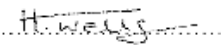
Amendment 2.

Subsequent to receipt of ethical approval above, I, the applicant, would like to request the following amendment/s to my original proposal.

- 1) Having recruited for the research over the past year, establishing the presence of psychosis in parents with bipolar disorder has presented some challenges; predominantly due to young people being familiar with the diagnosis but unsure about terminology around symptoms. Having liaised with staff within services from which young people are being recruited, it appears that the impact of stigma associated with psychosis has also influenced young people's willingness to identify themselves as eligible to take part (particularly within group settings). In view of this, I am proposing the amendment of eligibility criteria to include young people with a parent with bipolar disorder and remove exclusion criteria around recruiting young people where psychosis is not a feature: *'Young people aged 12-18 years (inclusive) who identify themselves as having at least one parent with experience of psychosis, a schizophrenia-type disorder or bipolar disorder'* (to be included). This amendment will not change the study aims but hopes to reduce the impact of stigma associated with psychosis and enable young people with a parent with a diagnosis of bipolar disorder to take part (whether or not psychotic features are known). Participant, parent and staff information has been slightly amended to reflect this change. These documents are attached and amendments have been highlighted in yellow.
- 2) With the aim of making the research more accessible to young people and enabling them to choose a method of contact that best suits them, I am proposing to give young people the option to provide verbal consent for staff to pass on their chosen method of contact (and relevant contact details) to enable the researcher to contact them (if they prefer). Should this be the case, young people will not be contacted within 24 hours of receiving participant information.

I would be very grateful for your review of these amendments.

Many thanks

Signature: 

Date: 14/11/2016

2nd Amendment

I can confirm that the above amendment has been reviewed.

- a. Ethical issues have been satisfactorily addressed and no further response from the applicant is necessary.

Signature: 

Position: Lecturer in Clinical Psychology, Ethics Tutor

Date: 17/11/16

Amendment 3.

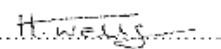
THIRD AMENDMENT: 31/01/2017

Subsequent to receipt of ethical approval above, I, the applicant, would like to request the following amendment/s to my original proposal.

With the aim of meeting sample size requirements for this study, as outlined in the original form, necessary ethical approval has now been sought for recruitment of participants through NHS services. The study has been reviewed and given a favourable opinion by the South East Scotland Ethics Committee for recruitment through NHS services. Please see REC / IRAS reference below:

REC reference: 17/SS/0007
IRAS project ID: 204617

Many thanks

Signature: 

Date: 31/01/2017



CLINICAL PSYCHOLOGY Research Ethics

Tue 31/01, 17:29

WELLS Holly; TAYLOR Emily



Reply all | v

Dear Holly,

Thank you for the update. We can simply log this on the system and add to the existing approval.

Best wishes,

Angus

Angus MacBeth
Lecturer in Clinical Psychology
Ethics Tutor

Appendix I (3). Confirmation of NHS South East Scotland Research Ethics Committee approval (conditional and final letter).

Lothian NHS Board

**South East Scotland Research
Ethics Committee 01**



Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

*Personal/contact
details removed*

16 January 2017

*Personal/contact
details removed*

Dear Miss Wells

Study title: Supporting Young People with a Parent with Experience of Psychosis: Understanding Their Experiences and Needs
REC reference: 17/SS/0007
IRAS project ID: 204617

The Research Ethics Committee reviewed the above application at the meeting held on 11 January 2017. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

*Personal/contact
details removed*

23 January 2017

*Personal/contact
details removed*

Dear Miss Wells

Study title: Supporting Young People with a Parent with Experience of Psychosis: Understanding Their Experiences and Needs
REC reference: 17/SS/0007
IRAS project ID: 204617

Thank you for your letter of 20 January 2016. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 16 January 2017

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
GP/consultant information sheets or letters [Letter to GP_v.1_Jan.17]	1	20 January 2017
Participant consent form [L - Participant Consent Form]	2	20 January 2017
Participant information sheet (PIS) [G - Participant Information Leaflet]	2	20 January 2017

Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [A - Flyer]	1	30 November 2016
Copies of advertisement materials for research participants [B - Poster (Parent)]	1	30 November 2016
Copies of advertisement materials for research participants [C - Poster (Young Person)]	1	30 November 2016
Copies of advertisement materials for research participants [D - Website Pages (Example)]	1	30 November 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [EL Insurance Certificate]	1	19 November 2016
GP/consultant information sheets or letters [E - Information for Staff]	1	30 November 2016
GP/consultant information sheets or letters [Letter to GP_v.1_Jan.17]	1	20 January 2017
Interview schedules or topic guides for participants [M - Interview Schedule]	1	30 November 2016
Other [Insurance Letter: PL confirmation]	1	19 November 2016
Other [I - Eligibility Screening Tool]	1	30 November 2016
Other [K - Post Interview Form]	1	30 November 2016
Other [N - Data Management Plan]	1	30 November 2016
Other [O - Participant Debrief]	1	30 November 2016
Participant consent form [L - Participant Consent Form]	2	20 January 2017
Participant information sheet (PIS) [H - Parent Letter (recruited through adult services)]	1	17 November 2016
Participant information sheet (PIS) [H - Parent Letter (recruited through young people's services)]	1	17 November 2016
Participant information sheet (PIS) [G - Participant Information Leaflet]	2	20 January 2017
REC Application Form [REC_Form_16122016]		16 December 2016
Referee's report or other scientific critique report [P - Feedback Academic Staff]	1	
Referee's report or other scientific critique report [Q - Ethical Review Feedback]	1	
Research protocol or project proposal [Study Protocol_Nov16_v.1]	1	17 November 2016
Summary CV for Chief Investigator (CI) [CV_Holly Wells]	1	17 November 2016
Summary CV for supervisor (student research) [CV_Dr Emily Taylor]	1	17 November 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [F - Recruitment Flowchart]	1	01 December 2016
Summary, synopsis or diagram (flowchart) of protocol in non technical language [J - Consent Process Flowchart]	1	30 November 2016

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

Yours sincerely

A handwritten signature in black ink, appearing to read 'S. Wyllie', with a stylized flourish at the end.

Sandra Wyllie
REC Manager

Personal/contact details removed

Appendix I (4). Confirmation of R&D management approval (NHS Fife).



Personal/contact details removed

Dear Miss Wells

**Project Title: Supporting Young People with a Parent with Experience of Psychosis:
Understanding Their Experiences and Needs**

Thank you for your application to carry out the above project. Your project documentation (detailed below) has been reviewed for resource and financial implications for NHS Fife and I am happy to inform you that NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
Copies of advertisement materials for research participants [A -Flyer]	1	30 Nov 2016
Copies of advertisement materials for research participants [B -Poster (Parent)]	1	30 Nov 2016
Copies of advertisement materials for research participants [C -Poster (Young Person)]	1	30 Nov 2016
Copies of advertisement materials for research participants [D -Website Pages (Example)]	1	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [EL Insurance Certificate]		19 Nov 2016
GP/consultant information sheets or letters [E - Information for Staff]	1	30 Nov 2016
GP/consultant information sheets or letters	1	20 Jan 2017
Interview schedules or topic guides for participants [M – Interview Schedule]	1	30 Nov 2016
Other [Insurance Letter: PL confirmation]	1	19 Nov 2016
Other [I - Eligibility Screening Tool]	1	30 Nov 2016
Other [K - Post Interview Form]	1	30 Nov 2016
Other [N - Data Management Plan]	1	30 Nov 2016
Other [O - Participant Debrief]	1	30 Nov 2016
Participant consent form [L - Participant Consent Form]	2	20 Jan 2017
Participant information sheet (PIS) [H - Parent Letter (recruited through adult services)]	1	17 Nov 2016
Participant information sheet (PIS) [H - Parent Letter (recruited through young people's services)]	1	17 Nov 2016

Appendix I (5). Confirmation of R&D management approval (NHS Lanarkshire).



Personal/contact details removed

Dear Miss Wells

Project title: Supporting Young People with a Parent with Experience of Psychosis: Understanding Their Experiences and Needs

R&D ID: L16126

NRS ID Number: NRS16/204617

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

<i>Personal/contact details removed</i>	ROLE
	Local Collaborator

For the study to be carried out you are subject to the following conditions:

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and the Data Protection Act 1998.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.cso.scot.nhs.uk/> or the Research & Development Intranet site: <http://firstport2/staff-support/research-and-development/default.aspx>)

Appendix I (6). Confirmation of R&D management approval (NHS Forth Valley)

NHS Forth Valley



Personal/contact details removed

Dear Miss Wells

Study title: Supporting Young People with a Parent with Experience of Psychosis: Understanding Their Experiences and Needs

REC reference: 17/SS/0007

Following the favourable opinion from the South East Scotland Research Ethics Committee 01 on 16 January 2017, I am pleased to confirm that I formally gave Management Approval to the study above on 02 February 2017. I note that NHS Forth Valley will be a Participant Identification Centre, and the only local activity will be putting up posters and distributing leaflets.

This approval is granted subject to your compliance with the following:

1. Any amendments to the protocol or research team must have Ethics Committee and R&D approval (as well as approval from any other relevant regulatory organisation) before they can be implemented. Please ensure that the R&D Office and (where appropriate) NRS are informed of any amendments as soon as you become aware of them.
2. You and any local Principal Investigator are responsible for ensuring that all members of the research team have the appropriate experience and training, including GCP training if required.
3. All those involved in the project will be required to work within accepted guidelines of health and safety and data protection principles, any other relevant statutory legislation, the Research Governance Framework for Health and Community Care and ICH-GCP guidelines. A copy of the Framework can be accessed via the Chief Scientist Office website at: <http://www.cso.scot.nhs.uk/Publications/ResGov/Framework/RGFEdTwo.pdf> and ICH-GCP guidelines may be found at <http://www.ich.org/LOB/media/MEDIA482.pdf>
4. As custodian of the information collected during this project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT security policies, until the destruction of this data.



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After the Interview: Points to Remember

If you become upset or worried about something, you can talk to:

-
-
-

Don't forget that you can also contact your GP if you are really worried about something.

There are also some links to supports and organisations you may find helpful on the website:

<http://hwells3.wix.com/research>



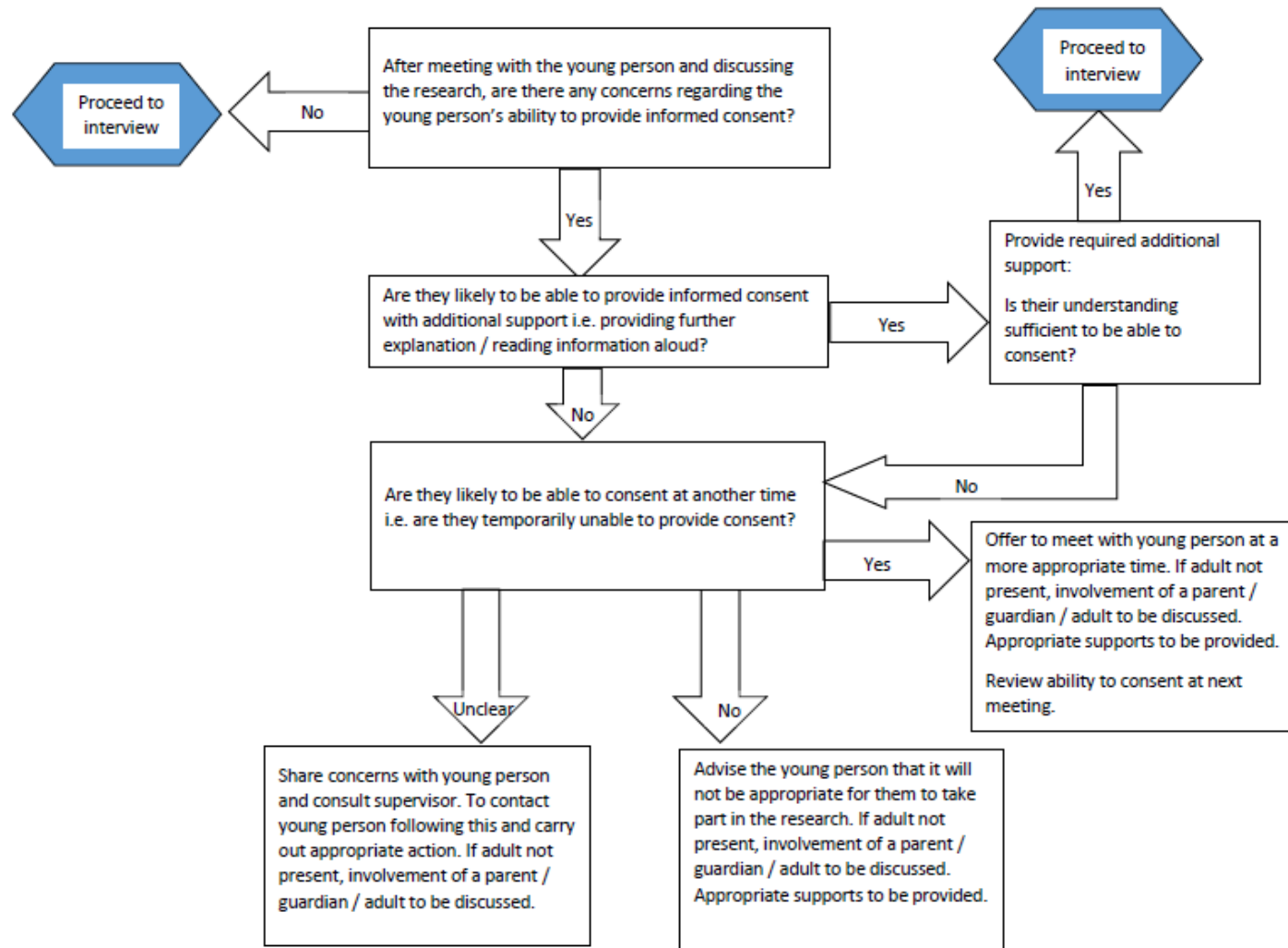
Thank you once again for taking part in the research – your views are very much valued and your participation is greatly appreciated!

Holly

Appendix K. Consent

(1) Consent process flowchart.....	p.196
(2) Consent form (NHS).....	p.197
(3) Consent form (third sector).....	p.199

Appendix K (1). Consent process flowchart



Appendix K (2). Consent form NHS

Young People with a Parent with Experience of Mental Illness_v2_Jan. 2017. Page 1 of 2



Participant Consent Form

PART A

Please initial the boxes you agree with. If there is anything that you do not agree with, let me know and we can talk some more. If there is anything that doesn't make sense, just ask.

☐

I have read and understood the participant information leaflet (v2. Jan. 17).

☐

I have been given the opportunity to discuss the research and ask questions.

☐

I have been given the answers I need.

☐

I have been given enough information about the research.

☐

I understand that my participation is entirely voluntary.

☐

I understand that I can tell the researcher at any time during the conversation if I want to stop or not take part.

☐

I understand that the results of the research may be published in a journal or used in presentations but that nobody will be able to tell that I was involved.

☐

I give permission for the interview to be audio recorded.

☐

I understand that relevant sections of data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsor(s) (NHS Lothian and the University of Edinburgh) or from the/other NHS Board(s) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records.

☐

I have discussed the option of being contacted again for a second interview. I understand that I will only be contacted for this purpose if the researcher thinks that another conversation would be helpful.

☐

I give permission for the researcher to contact me to discuss the option of a second interview. I am happy for the researcher to contact me by:

☐

Phone:

☐

Email:

☐

I do not want to be contacted again by the researcher to discuss the option of a second interview.

<input type="checkbox"/>	I have discussed the option of the researcher contacting my GP to let them know that I have taken part in this research.
<input type="checkbox"/>	I would like the researcher to contact my GP to let them know that I have taken part in this research and have seen an example of the letter that will be sent. I have provided my GP contact details and date of birth so that the researcher can write to my GP for this purpose.
	Name of GP:
	GP Practice:
	Date of birth:
<input type="checkbox"/>	I do not want the researcher to contact my GP to let them know that I have taken part in this research.
<input type="checkbox"/>	I understand what I am being asked to do and agree to take part.
PART B (only to be completed by people under the age of 16 years)	
If you are under the age of 16 years, please initial the most relevant box below:	
<input type="checkbox"/>	A parent / guardian knows about my participation in the project and is happy for me to take part.
<input type="checkbox"/>	I have made a decision not to involve a parent / guardian in my participation with the project.
PART C	
Participant's name:	
Participant's signature:	
Name of person obtaining consent:	
Signature of person obtaining consent:	
Date:	

Original (x1) to be retained in site file. Copy (x1) to be retained by participant.

Appendix K (3). Consent form (third sector)



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Participant Consent Form

PART A	
Please initial the boxes you agree with. If there is anything that you do not agree with, let me know and we can talk some more. If there is anything that doesn't make sense, just ask.	
<input type="checkbox"/>	I have read and understood the participant information leaflet.
<input type="checkbox"/>	I have been given the opportunity to discuss the research and ask questions.
<input type="checkbox"/>	I have been given the answers I need.
<input type="checkbox"/>	I have been given enough information about the research.
<input type="checkbox"/>	I understand that my participation is entirely voluntary.
<input type="checkbox"/>	I understand that I can tell the researcher at any time during the conversation if I want to stop or not take part.
<input type="checkbox"/>	I understand that the results of the research may be published in a journal or used in presentations but that nobody will be able to tell that I was involved.
<input type="checkbox"/>	I understand what I am being asked to do and agree to take part.
PART B (only to be completed by people under the age of 16 years)	
If you are under the age of 16 years, please initial the most relevant box below:	
<input type="checkbox"/>	A parent / guardian knows about my participation in the project and is happy for me to take part.
<input type="checkbox"/>	I have made a decision not to involve a parent / guardian in my participation with the project.
PART C	
Participant's name:	
Participant's signature:	
Name of person obtaining consent:	Holly Wells
Signature of person obtaining consent:	
Date:	

Appendix L. Initial interview guide

I wonder if you could tell me a bit about your Mum / Dad's X (*insert young person's description of PMI*)?

Do you talk to other people about it?

Who?

How do you explain it?

How do other people react?

What are the most difficult bits?

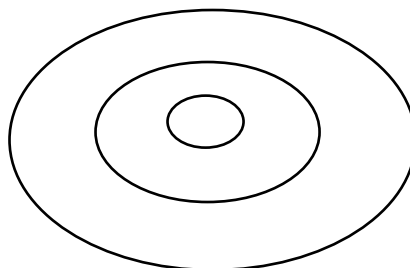
Who do you think is responsible when things are more difficult?

If you felt you needed it, who would you go to first for help?

How does that go?

If you imagine that your Mum / Dad is at the centre of this (point to diagram) – who is around to support them? (Explaining that the further towards the centre someone is placed, the more supportive / involved they are).

Where would you fit in?



How has your role in your family changed over time?

If your friend told you that their Mum / Dad had X (*insert young person's description of PMI*), what kind of advice would you give them?

Appendix M. Example of transcription and analysis

Transcript excerpt	Initial coding	Focused coding / categories
<p>I: and can you remember what you thought about that (Mum hearing voices & responding) at that time?</p> <p>P: I was really scared because I thought there was actually someone in the house and I thought there was somebody watching us which made me really scared – I wouldn't go in the bath or anything because I thought somebody was watching us and they would be watching me there.</p> <p>I: Did you have any thoughts about who was watching you?</p> <p>P: I thought it was...my Mum was really attached to my Gran. My Gran and my Grandpa but they passed away ...so I thought my Mum was trying to talk to them and I thought my Grandpa was like always around because she always used to see my Grandpa.</p> <p>I: and did Mum speak to you about it?</p> <p>P: I didn't find out until I was 11 years old.</p> <p>I: Who was it that told you about it, can you remember?</p> <p>P: I remember my Mum telling me that she had a problem and she couldn't help it but it was part of her and that I was not to get scared and nobody was in the house and when I was 12 the Dr said it was psychosis and that my Mum was really ill and it wasn't her fault but she just needed some mental help.</p> <p>I: Sure, okay - that's really interesting, I'd like to hear a bit more about that (name of participant). So, you were told when you were 11 by Mum that she had some difficulties and what did you make of it then?</p>	<p>Feeling scared that someone else was around Worrying that someone was watching</p> <p>Making sense of psychosis</p> <p>Finding out</p> <p>Speaking to Mum</p> <p>Speaking to the Doctor</p>	<p>Feeling worried, scared & confused</p> <p>Seeking & Having information</p> <p>Speaking to others</p>

<p>P: I was, I was, I thought she was just trying to cover up that she was talking to people but then when the days passed on I knew that it was a problem and that I didn't want to talk to her at the time because I didn't want to upset her.</p> <p>I: Okay, sure.</p> <p>P: But she was getting bad, badder and badder and then I did talk to her and she said that the Dr would explain everything to me when I was older and I wasn't to worry and just forget about it.</p> <p>I: Okay, and then you said that when you were 12 the Dr spoke about it and they said it was psychosis. Can you remember what they said to you?</p> <p>P: I can remember them saying that my Mum had a mental illness and it was called psychosis and that she wouldn't be the same that she would talk to herself like someone was in with her; that she would walk around like someone was there with her and that the Dr's could help her by giving her medication but I was just trying to help my Mum to my best ability.</p> <p>I: and can you remember how you thought about it or felt about it at that time?</p> <p>P: I was upset because I was, my Mum had been going through it for a long time and I was upset that I didn't realise and could've helped her.</p> <p>I: Okay, can you tell me a bit more about that?</p> <p>P: When I was 12, when I found out, I used to, I wouldn't let her get out of bed, I like done everything for her, that's when I became a young carer. I done everything for her because I thought, I felt guilty that I didn't realise that I basically was watching her when she was suffering.</p>	<p>Thinking that Mum had other powers Not talking; not wanting to upset Mum</p> <p>Talking to Mum when things got worse Finding out more when I'm older</p> <p>Getting an explanation Thinking that Mum would be different Being aware medication can help Doing my best to help</p> <p>Feeling responsible</p> <p>Feeling upset about not knowing Wanting to help Becoming a young carer Feeling guilty</p>	<p>Being perceived as too young</p> <p>Seeking & having information</p> <p>Having a role in parent's care & perceiving responsibility</p>
---	--	---

Appendix N. Summary of completed written task

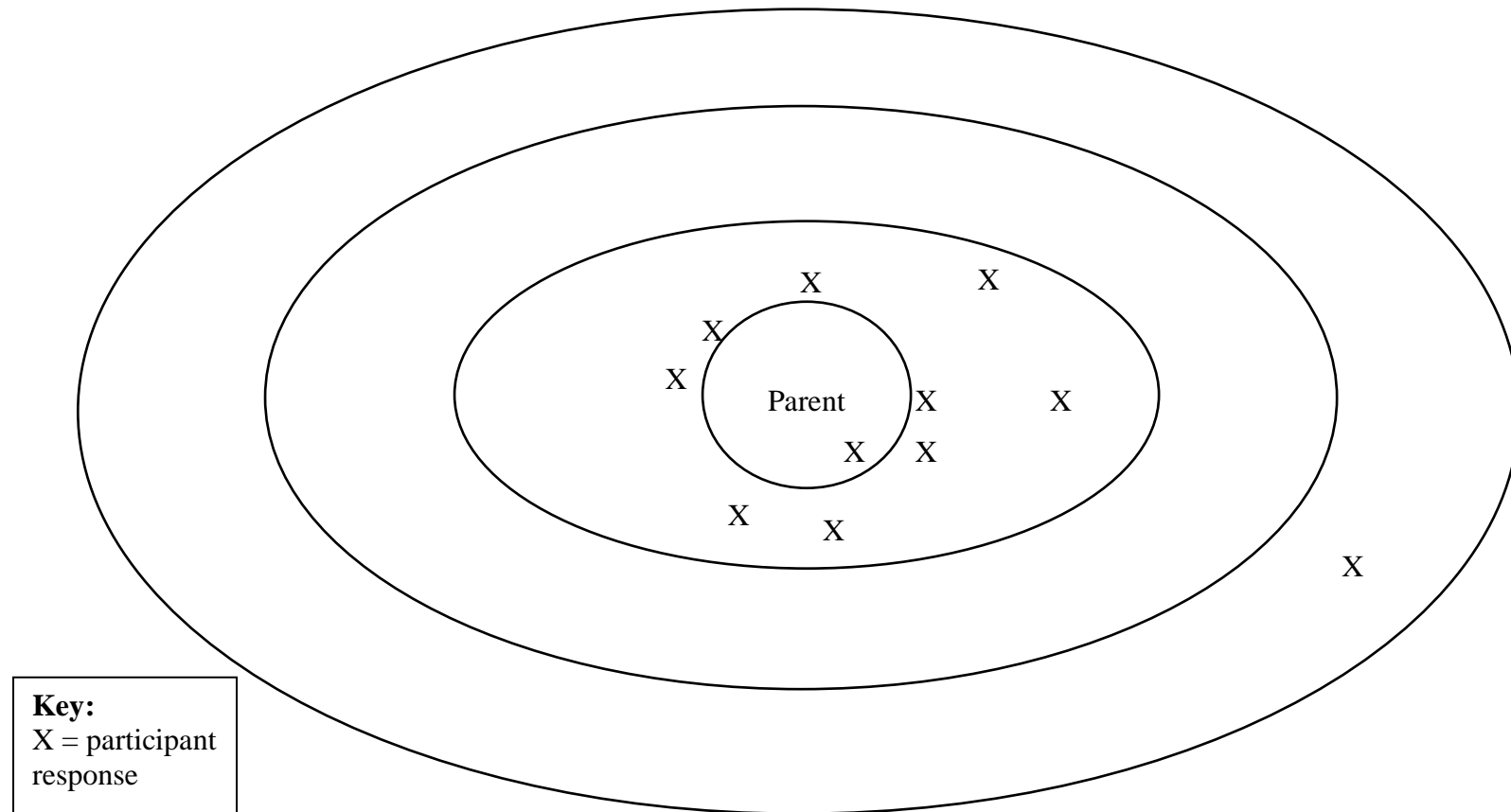


Figure 2.2. An indication of participant responses when asked where they would place themselves in the context of their parent's support network (N = 11).